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ABSTRACT

Testimony presented in this document covers (1) current initiatives in the Public Health Service agenda to promote and protect the health of mothers and infants and to implement specific prevention activities in child health; (2) key issues in outcome and prevention along the human growth line; (3) recent neuroscience research having implications for the development of cognitive processes; (4) fetal alcohol syndrome; (5) emotional development and necessary elements of preventive intervention programs; (6) research into infant mortality, low birth weight, teenage problems associated with the high incidence of pregnancy, and prenatal care; (7) low birth weight in the low income minority population; (8) historical dimensions of the role of nutrition in preventive health care and evidence linking nutrition and pregnancy outcomes; and (9) results of longitudinal studies of early childhood education concerning the cost effectiveness of early intervention. Approximately half of the text is an administrative petition to the United States Department of Health and Human Services to reduce the incidence of low birth weight and resulting infant mortality. The petition proposes remedies, provides new data on the current status of maternal and infant health, highlights results of programs proven successful in increasing birth weight and lowering infant mortality, and includes a cost analysis of providing comprehensive prenatal care to those in need. (RH)

PREVENTION STRATEGIES FOR HEALTHY BABIES AND HEALTHY CHILDREN

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HEARING

BEFORE THE

SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES HOUSE OF REPRESENTATIVES

NINETY-EIGHTH CONGRESS

FIRST SESSION

HEARING HELD IN WASHINGTON, D.C., ON
JUNE 30, 1983

Printed for the use of the
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PREVENTION STRATEGIES FOR HEALTHY BABIES AND HEALTHY CHILDREN

THURSDAY, JUNE 30, 1983

House of Representatives,
Prevention Strategies Task Force,
Select Committee on Children, Youth, and Families,
Washington, D.C.

The select committee met, pursuant to call, at 9 a.m., in room 2358, Rayburn House Office Building, Hon. William Lehman (chairman of the task force) presiding.

Present: Representatives Miller, Lehman, Schroeder, Boggs, Mikulski, Weiss, Leland, Levin, Rowland, Sikorski, Wheat, Marriott, Bliley, Wolf, Johnson, McKernan, and Vucanovich.

Staff present: Alan J. Stone, staff director and counsel; Ann Rosewater, deputy staff director; Karabelle Pizzigatti, professional staff. Christine Elliott-Groves, minority staff director; and Joan Godley, committee clerk.

Mr. Lehman. In order to get the committee underway, we will not officially call the committee to order because we need two people here to make it official, but I am going to suspend the rules for just a moment. But I would like for the court reporter to take my opening statement down, and we will call the meeting to order after I read my opening statement.

I am pleased to welcome all of you to the first hearing of the Prevention Strategies Task Force.

Today begins our effort to gather the best available information on early childhood development, on how to best enhance that development, and how we can achieve significant savings as a nation by preventive approaches.

We are especially fortunate to bring together eminent scientists and researchers as well as administration officials. They will present us with the results of the latest scientific studies on the physical and mental development, the social and emotional development of our youngest citizens, as well as the crucial role parents play in this development.

We will learn that many early influences on the lives of children—nutrition, behavior or access to medical and other care—may preview the strengths or difficulties affecting children as they grow and when they are adults.

We will also learn about successful efforts, particularly in the most recent decades, to prevent disabilities and disease among children. Many of these efforts have been based on the best available

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research, and have been promoted by Federal investments and Federal activity. We have much to learn from these successes.

Today's hearing focuses heavily on preventing problems—and enhancing well being—among young children. As this series of hearings continues, we will, of course, look carefully at the latest scientific evidence about older children and adolescents' development, and the best models for preventing problems to which they are most prone.

This hearing will provide an overview of the many issues encompassed by the Prevention Strategies Task Force. It is just a beginning—really just the tip of the iceberg—but offers enormous hope for the opportunities this Nation has to assure the health and wellbeing of our young people.

We now have a quorum, and the chairman of the full select committee is here. I now call the task force to order. Without objection, I would like to lay down the following rules that we will abide by today. Following my opening statement, the first opportunity would then go to Mr. Bliley, the ranking member of the task force on the Republican side, then we will go to Chairman Miller of the full committee, and then to the ranking member of the full committee, Mr. Marriott. Then we will hear the opening statements of each of our panels and then each member, beginning with the chairman of the task force and the ranking member, the chairman of the full committee and ranking member, and those members that may be here on both sides will have 5 minutes to question the witnesses.

We will work under the 5-minute rule so that they can ask one or more questions. But we will be limited to the 5-minute rule so that we can assure each person on the committee that they will have at least a chance today to ask one question and not be shut out entirely.

So unless there is objection to these rules, we will now proceed, and I will yield to my good friend, the chairman of the select committee, Hon. George Miller of California.

Chairman Miller. I commend the chairman and ranking minority member for organizing this hearing in an expeditious manner. Prevention is a subject the chairman and I have focused on for several years, and I am delighted to join him this morning in this, his initial hearing.

There isn't a member of this committee, nor an adult person anywhere in the United States for that matter, who hasn't learned in the last 20 years about the risk factors inherent in smoking, drinking, eating to excess, and not exercising. Not only have millions changed their habits, but there is overwhelming evidence that the rate of certain killer diseases, like coronary disease, has diminished considerably as a result. Each of these fundamental changes came about after prevention research revealed the risk factors—research funded often by the Government, the agencies represented here today.

Now, of course, we have major new industries prospering from the changes in public awareness, and almost unanimous agreement among the medical profession on the importance of risk reduction. This example of Congress, the executive branch, and the business sector, all doing their job, is a success story that continues to unfold. These efforts, however, have been aimed at well, adult people, people who can make choices.

I would like to ask the one question that doesn't get asked often enough around here—what about the children?

What about promoting health for dependent, developing infants, who are inherently vulnerable, who have no habits to change, who are not yet members of the market place?

Government has a positive role to play today in addressing that question. That much should be axiomatic. Look how profoundly immunizations have cut down on childhood diseases and disability. To take just one example.

We have had something to do with children's health probably since the first White House Conference on Children, held by William Howard Taft, in 1909. The Social Security Act of 1935 followed, then many landmark bills in the 1960's and 1970's, each addressing some basic health need of children.

These are, however, the 1980's. And while children continue to be children, the circumstances in which they live continue to change. Some of those changes are good: We know much more about risks to children and how to prevent them. Some are bad: We can't afford the old way of doing business. Some are truly frightening: Even more children, one in four, may live in poverty by 1990, depending on the economy. And, some are just facts of life: Families have changed, and will continue to change, profoundly.

These are the new social and economic realities in America. We can look upon them as opportunities, or we can sit back and wring our hands.

From my perspective, the chance to reduce infant mortality and morbidity, improve the overall development of children, reduce future healthcare costs by tens-of-millions of dollars is too good to pass up. The fact that we can save billions in future dependency costs should serve to motivate us as well. In short, we can do good and do well at the same time.

Today's witnesses will help us proceed in the right direction. Respected research scientists will summarize the latest findings on the physical and neurological development of infants and children. Among the most important points they will make this morning are:

For every dollar invested in one year of high quality preschool education for economically disadvantaged children, the returns to society in lowered costs for support services and higher worker productivity total $4.75.

Nutritional supplements and health care during pregnancy clearly help reduce the incidence of low birth weight infants (low birth weight is the leading cause of neonatal mortality and disability).

For every $1 spent on the special supplemental feeding program for women, infants and children, $3 is saved in hospitalization costs for low birth weight babies. The savings are undoubtedly much greater when long-term costs of care for disabilities resulting from low birth weight are counted as well.

Fetal alcohol syndrome is the leading preventable cause of mental retardation, and it's the third leading cause of mental retardation overall.

Studies now show that even moderate levels of alcohol consumption by pregnant woman can adversely effect the health of the fetus. It is impossible to set a "safe" level of drinking for pregnant women.

As a result of recent research, we can now detect emotional disturbances in infants as young as two months old. Such emotional problems, if left untreated, can significantly impair a child's ability to concentrate and learn, to control impulses, and to form and maintain loving and responsible human relationships.

Finally, we have agreed, in a bipartisan fashion, to hold to least seven more hearings, in Washington and around the country in the next few months. Many members have expressed their interest in holding additional hearings during the same period. Allowing for budgetary and scheduling constraints, we will do our best to honor each request. The schedule will be printed as part of the record.

Mr. LEHMAN. I now call on, for an opening statement, the ranking minority member of our task force, Mr. Bliley of Virginia.

Mr. BLILEY. Thank you, Mr. Chairman.

First of all, I would like to congratulate the majority for putting together such a fine panel of witnesses for our hearing today. We will hear from a variety of experts, each representative of a profession dealing with the problems of infant and child health. Our witnesses come from within the administration and without, from the medical profession, research facilities, private foundations and a public interest group. Information of many kind will be presented: medical, statistical, psychological, and economic. We will try to be equal to the challenge they offer.

Before we begin, however, I would like to take the opportunity to point out a fact of which I am certain that the majority is already generally aware, that is, that the subject of prevention strategies for healthy babies and children will not be covered completely, even by these expert panels. Indeed, we all recognize that adequate coverage of this subject matter would be difficult, if not impossible, in a hearing lasting only 1 day.

But the particular point I intend to make is that there seems to be one important area on which we have yet to focus even after our discussion today; and that area is in the realm of human causes. We might talk for hours about the biology of the brain, the development of the child in the uterus, and the nutritional requirements for the delivery of a normal healthy baby to a normal healthy mother. We can learn about Government programs which seek to supply the medical, nutritional, and economic needs of mothers and children. Yet, still, there are some important aspects of the infant health problems which these considerations leave unaddressed.

The most serious problem we do not address is teenage pregnancy. The facts are that the age of the mother and even her marital status comprise, along with the medical indicators, signficant factors in determining the risk that she will give birth to an unhealthy baby. According to the Joseph P. Kennedy, Jr. Foundation, a 16-year-old girl is twice as likely to give birth to a low birth weight or premature baby than is a mother in her twenties.

Two-thirds of the 250,000 low birth weight babies born annually are not undernourished, but simply premature. Prematurity is a hazard for which teenagers are at a significantly greater risk than other women. According to the 1981 HHS Research Forum on Children and Youth, premature births account for 70 percent of all perinatal morbidity and mortality.

This phenomenon of adolescent pregnancy, then, is what I would call one of the human causes affecting infant health. It differs from a medical cause in that it is not the result of malnutrition, ill health, or disability but of the choices and actions of individuals.

I am certain that few of us would disagree with the statement that young teenagers, whose bodies are not yet fully matured, should not be conceiving babies for whom they are neither physically or emotionally prepared to care. Yet they are doing just that, and in greater and greater numbers every year.

It is with this particular fact in mind, and its causal relation to the subject of our current hearing, that I, along with the other minority members, have asked the chairman of this task force for a second day of hearings on this same subject, and the opportunity to call our own witnesses at this time.

The chairman has agreed to our request and though the exact date of those hearings has not yet been determined, he has promised that he will do all within his power to arrange for the hearings to take place during the second week after our July 4th recess.

I would like to thank the chairman for his cooperation in this matter, and I would also like to deliver to him at this time, in compliance with rule XI, clause 2, a letter from all of the minority members of the task force requesting these witnesses to be invited to testify.

If we genuinely share a concern about healthy children, then we should look without bias at all of the causes of their health problems.

Thank you very much.

Mr. LEHMAN. Thank you.

We will have this hearing. Mr. Bliley will submit the list of witnesses and we will select those witnesses out of that list that we think will be most productive. I can assure Mr. Bliley that we are as much concerned about teenage pregnancy on this side of the aisle, and as personally as anyone could possibly be. In my own area, 28-year-old grandmothers are not a rarity, and this is something that I see as a very serious problem in our society. I assure you my full cooperation.

Mr. BLILEY. Thank you.

Mr. LEHMAN. At this time I would like to call on our hearing panel for the opening statements, and I don't know whether each member has an opening statement, but I would hope that one of you would have the more or less encompassing opening statement. If you would like to, you can summarize it for the record, and your full statement will be inserted in the record without objection from the panel members.

STATEMENT OF EDWARD N. BRANDT, JR., ASSISTANT SECRETARY FOR HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY DR. MORTIMER LIPSETT, DIRECTOR, NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT, AND DR. ROBERT GRAHAM, ADMINISTRATOR, HEALTH RESOURCES AND SERVICES ADMINISTRATION

Dr. **Brandt**. Thank you very much, Mr. Chairman. I am Dr. Edward Brandt, the Assistant Secretary for Health of the Department of Health and Human Services. I am accompanied this morning on my right by Dr. Robert Graham, who is Administrator of the Health Resources and Services Administration, and on my left Dr. Mortimer Lipsett, who is Director of the National Institute of Child Health and Human Development of the National Institutes of Health.

I will summarize our opening statement and then we will, of course, be available to answer any questions that you or other members of the committee may have.

The Public Health Service and the Department of Health and Human Services are pleased to participate in this first hearing of the Select Committee on Children, Youth, and Families Task Force on prevention strategies. We are gratified to note the emphasis that your committee intends to place on prevention. As you know, the Public Health Service has long been an advocate of prevention, and that theme runs prominently through the programs and activities of our agencies

Before I turn to a discussion of our specific prevention activities in child health, it would be helpful to place our current initiatives, which seek to promote and protect the health of mothers and infants, in the context of the broader Public Health Service agenda in health promotion and disease prevention.

The roots of that agenda are to be found in *Healthy People*, the Surgeon General's Report on Health Promotion and Disease Prevention. This report introduced a set of measurable goals for the improvement of the health of Americans in each of the five stages of life.

Healthy People identified 15 substantive priority areas within which progress would advance us toward realization of our goals.

The area of pregnancy and infant health embodies 19 specific objectives which are attached to my statement. In the main, these objectives emphasize the reduction of mortality in the period surrounding birth and during the first year of life.

Let's look briefly at some recent statistics.

There are 52 million women of reproductive age in this country. They had a total of 3.6 million live births and approximately 20,000 fetal deaths in 1980. Included in those numbers are at-risk groups: The more than 10,000 babies born to adolescents under 15 years of age; the over 24,000 infants born to women of 40 years of age and older; and those 46,000 women who fail to receive—seek—prenatal care, particularly early prenatal care.

Complete mortality data for 1980 show that the infant mortality rate has declined to 12.6 deaths per 1,000 live births; however, the rate of 21.4 for Black infants is almost twice that for white infants.

Provisional data for 1982 show a further decline in infant mortality to 11.2 deaths per 1,000 live births. We are well on our way to achieving our goal set forth in *Healthy People*, and at the current rate we will easily pass that goal of 9 deaths per 1,000 live births well before 1990.

Improvements in health care and health status demand efforts extending far beyond federally sponsored programs. The private sector of medicine and other health professions, business and industry, educational institutions, voluntary organizations, and the public are all involved. We have joined with more than 60 other groups concerned with maternal and infant health to form the Healthy Mothers, Healthy Babies Coalition.

We know that multiple prevention factors, such as good nutrition, breastfeeding, early and regular prenatal care and abstaining from cigarettes and alcohol, contribute to good infant health. The Coalition addresses each of these prevention messages, stressing attention to high-risk women.

I will now address a number of Our Public Health Service prevention activities in child health. With funds from the MCH services block grant, all States are currently screening for phenylketonuria, or PKU.

Our maternal and child health program at the Health Resources and Services Administration [HRSA] has targeted special project funds to States with excessive infant mortality—and adolescent pregnancy—to assist the development of regionalized perinatal systems. These projects are currently funded in 24 States.

We are undertaking a variety of activities aimed at reducing the prevalence of undue lead absorption as well as severe lead poisoning in children.

In 1979, the maternal and child health program established accident and injury prevention as a high priority.

To assure transfer and application of these project experiences and results, three major activities have been undertaken. In cooperation with the Committee on Accident and Poison Prevention of the American Academy of Pediatrics, a nationwide program aimed at reducing childhood injuries and poisonings has been developed. This program is augmenting the AAP's "First Ride/Safe Ride" campaign stressing utilization of car safety carriers for infants. The injury prevention program launched on April 15, 1983, at the Academy's spring meeting.

The Centers for Disease Control, in cooperation with local health departments in Miami, Fla., and Pittsburgh, Pa, has also established two injury prevention demonstrations.

Each institute at the National Institutes of Health actively pursues both basic and applied research that shows promise of leading to methods of preventing or ameliorating diseases.

A major and continuing priority of the National Institute of Child Health and Human Development is the reduction of the incidence of low birthweight infants. The NICHD is seeking to identify biologic factors that predict women at risk for low birthweight infants, develop understanding and strategies for preventing maternal behavior that adversely affects fetal growth, describe the events precipitating labor, and finding ways of stopping premature labor.

The District of Columbia, in conjunction with NICHD, is beginning an intervention trial to ascertain whether the totality of good early prenatal care, nutrition, and the reduction of other fetal risk factors will reduce the percentage of low birthweight infants in the District.

The Institute has completed an 8-year major research study of the cause of the sudden infant death syndrome. No single biologic factor was identified. Those conditions associated with low birthweight also identify infants susceptible to SIDS.

The shift in breastfeeding from 25 percent in 1971 to 58 percent in 1981 has resulted from the publicity accorded the research findings that the constituents of human milk prevent disease and promote the well-being of the infant.

The 125,000 children born each year with major congenital defects mandate a major research effort in this area. Research is currently directed at vaccine development for cytomegalovirus [CMV], which is responsible for defects in about 5,000 infants yearly. A clinical trial of one of these vaccines is under consideration.

Birth defects are three times more frequent in infants of diabetic women than in infants of normal woman. NICHD is sponsoring a major clinical trial to determine whether careful control of diabetes before conception and during the first trimester, when the organs develop, will lower the incidence of birth defects.

NICHD research has led to routine neonatal screening for congenital hypothyroidism. Appropriate replacement of thyroid hormone now prevents mental retardation due to congenital hypothyroidism in about 1,000 infants annually.

Examples of research in prevention and child health in other NIH Institutes are:

Vaccine development to prevent infant diarrhea;

Prevention of neonatal hepatitis;

Prevention of late sequelae of juvenile diabetes mellitus;

Development of a safer vaccine for pertussis—whooping cough—and a number of other things which are outlined in my testimony, Mr. Chairman.

Turning to alcohol, in the last decade studies have yielded clear and compelling evidence that alcohol consumption during pregnancy poses a significant risk for the unborn child.

It appears clear that the incidence of fetal alcohol syndrome [FAS] in the United States is similar in magnitude to the incidence of Down syndrome and spina bifida; together, these constitute the leading known causes of birth defects with mental impairment. Of these, FAS is uniquely preventable.

Moderate drinking—for example, alcohol consumption at the level of two drinks per day—is associated with decreased birthweight and behavioral deficits. There is as yet no agreed upon definition of a safe level of alcohol consumption during pregnancy.

The National Institute on Alcohol Abuse and Alcoholism [NIAAA] is supporting 13 fetal alcohol research grants and anticipates funding future research on effects of binge drinking, mechanisms underlying adverse effects of alcohol on offspring, and long-range development of children born to mothers who drank during pregnancy.

NIAAA's public education efforts include the development of television, radio, and print materials on the fetal alcohol syndrome and alcohol-related birth defects, alcohol problems among women, and alcohol problems among youth.

Let me now turn to other childhood disease prevention programs of our Centers for Disease Control [CDC]. Great strides have been made in preventing childhood diseases through immunization. During the last 2 years, record low numbers of measels, mumps, rubella, polio, diphtheria, and tetanus have been reported in this country.

Diabetes affects over a half million women of childbearing age and 120,000 children under 20 years of age. In partnership with the States and other public and private organizations, CDC is involved in activities designed to prevent unnecessary disability and premature death from avoidable complications of diabetes.

Although tooth decay affects virtually every person in the United States, children are most vulnerable. Drinking optimally fluoridated water from birth reduced dental cavities by approximately two-thirds. CDC provides technical assistance to State and local health departments in initiating fluoridation programs and in assuring optimal levels of fluoridation in existing programs.

Tuberculosis in children—an indication of ongoing transmission in a community—continues to occur in the United States. A key concern is the fact that the tuberculosis incidence rate has failed to decline among children 0-14 years of age during the period 1976-81. From 1981 to 1982 the overall number of cases decreased by 6.8 percent; however, at the present time we do not know if the number of cases has decreased among children.

Gonorrhea, syphilis, chlamydia, and herpes simplex virus are considered the most important sexually transmitted diseases [STD] affecting children. In partnership with States and other public and private organizations, CDC is involved in activities designed to reduce the risk of STD infection and related complications in this vulnerable group.

In conclusion, Mr. Chairman, members of the committee, the health of our children has never been better. But the prevention programs of the Public Health Service are still of highest priority. We must continue to promote the benefits of preventive measures and positive health practices, and we must continue to work together. I have faith that we are fully capable of even greater achievement in maternal, infant, and child health.

But reaching the goals we have set for 1990 requires the collective efforts of the entire public health community—at the local, State and Federal levels. Promoting and protecting the health of the newborn is not only our responsibility, it is also the best investment we can make in the future good health of the American people.

That concludes my statement, Mr. Chairman. I and my colleagues will be delighted now to try to answer your questions.

Mr. **Lehman**. Thank you. Your full statement will be inserted in the record, or any statements of your colleagues as well.

[Prepared statement of Edward Brandt follows:]

PREPARED STATEMENT OF EDWARD N. BRANDT, JR., M.D., ASSISTANT SECRETARY FOR HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mister Chairman and Members of the Committee: It is a pleasure to participate in the first hearing of the Select Committee on Children, Youth and Families Task Force on Prevention Strategies. I am accompanied this morning by Dr. Robert Graham, Administrator of the Health Resources and Services Administration; and Dr. Mortimer Lipsett, Director of the National Institute of Child Health and Human Development, National Institutes of Health.

The Public Health Service and the Department of Health and Human Services are gratified to note the emphasis your Committee intends to place on prevention. As you know, the Public Health Service has long been an advocate of prevention, and that theme runs prominently through the programs and activities of our agencies.

Before I turn to a discussion of our specific prevention activities in child health, it would be helpful to place our current initiatives, which seek to promote and protect the health of mothers and infants, in the context of the broader Public Health Service agenda in health promotion and disease prevention.

The roots of that agenda are to be found in Healthy People, the Surgeon General's Report on Health Promotion and Disease Prevention. This report introduced a set of measurable goals for the improvement of the health of Americans in each of the five stages of life. Two of those age-based life stages encompass America's children. Our goals for 1990 are to reduce the level of infant mortality by 35 percent to fewer than 9 per 1,000 live births, and, for children ages 1 to 14 years, to reduce the mortality rate by 20 percent to fewer than 34 per 100,000.

In addition to articulating these goals, Healthy People, identified 15 substantive priority areas within which progress would advance us toward realization of our goals. While a number of these areas, such as immunization, smoking control, nutrition, and alcohol and drug misuse prevention have significant implications for the health of mothers and children, the single priority most immediately and uniformly relevant to our areas of mutual concern and interest today is that which deals with pregnancy and infant health.

The area of pregnancy and infant health embodies 19 specific objectives which are attached. In the main, these objectives emphasize the reduction of mortality in the period surrounding birth and during the first year of life. Other objectives seek to reduce the incidence of such problems as neural tube defects or fetal alcohol syndrome; reduce the rate of maternal mortality; and reduce factors which pose risks to the well-being of infants such as low birthweight.

Let's look briefly at some recent statistics.

There are 52 million women of reproductive age in this country. They had a total of 3.6 million live births and approximately 20,000 fetal deaths in 1980. Included in those numbers are at-risk groups: the more than 10,000 babies born to adolescents under 15 years of age; the over 24,000 infants born to women of 40 years of age and older; and those 46,000 women who fail to receive (seek) prenatal care, particularly early prenatal care.

Complete mortality data for 1980 show that the infant mortality rate has declined to 12.6 deaths per 1,000 live births; however, the rate of 21.4 for Black infants is almost twice that for white infants (11.0). More than two-thirds of these deaths occurred to infants less than 28 days old. Recent studies attribute much of the general decline in infant mortality and especially in weight specific mortality rates to advances in technology, regionalization of maternal and newborn services, the provision of risk-appropriate care, and changes in life style. Provisional data for 1982 show a further decline in infant mortality to 11.2 deaths per 1,000 live births. We are well on our way to achieving our goal.

A variety of socioeconomic conditions and long accepted attitudes bear upon the health conditions of mothers and children. We are certain that changes in habits of eating and drinking, improvements in nutrition and availability and use of proper prenatal and infant care can bring about significant, even dramatically positive results.

Healthy mothers, healthy babies

It is important to note that improvements in health care and health status demand efforts extending far beyond federally sponsored programs. The private sector of medicine and other health professions, business and industry, educational institutions, voluntary organizations—and the public—are all involved. We have joined with more than 60 other groups concerned with maternal and infant health to form the Healthy Mothers, Healthy Babies Coalition. Dedicated to helping continue the downward trend of infant mortality in the 1980s, the Coalition recognizes that by joining forces we can more effectively influence health care professionals to counsel their patients and encourage pregnant women to practice good health habits. We know that multiple prevention factors, such as good nutrition, breastfeeding, early and regular prenatal care and abstaining from cigarettes and alcohol, contribute to good infant health. The Coalition addresses each of these prevention messages, stressing attention to high risk women, through educational programs and strategies jointly developed and implemented. For example, a national effort to encourage physicians to counsel their patients about breastfeeding is being coordinated by the American Academy of Pediatrics and will be implemented by many of the Coalition members, including the Public Health Service, USDA's Food and Nutrition Service, and the American College of Obstetricians and Gynecologists.

The National Center for Health Statistics recently completed the 1980 National Natality Survey and National Fetal Mortality Survery. These surveys were designated to investigate a wide variety of factors believed to be associated with pregnancy outcome and infant health. Preliminary data from these surveys are now available. The findings suggest that women are becoming aware of health risks in pregnancy and are altering their habits to diminish the risks.

I will now address a number of our Public Health Service prevention activities in child health.

With funds from the MCH Services block grant, all States are currently screening for phenylketonuria or PKU. We are able now to detect cases of PKU and institute successful dietary treatment to avoid the mental retardation and possible institutionalization associated with the condition.

Our Maternal and Child Health program at the Health Resources and Services Administration (HRSA) has targeted special project funds to States with excessive infant mortality (and adolescent pregnancy) to assist the development of regionalized perinatal systems. These projects, are currently funded in 24 States and their activities are now being integrated with MCH service block grant programs. The continuation of services and the decline in infant mortality indicate that these IPO projects, along with other factors, have had positive results.

With respect to the serious childhood lead poisonings, we are undertaking a variety of activities aimed at reducing the prevalence of undue lead absorption as well as severe lead poisoning in children. To achieve this goal, we have prepared and disseminated informational and guidance materials to the State health agencies; identified research needs; and funded studies to increase the cost-effectiveness of lead screening, to simplify the diagnostic procedures and to reduce the dangers of chelation therapy. The Centers for Disease Control (CDC) provides technical assistance to State programs for the prevention of lead toxicity in children and monitors the impact of lead in the environment on lead blood levels in children.

Another prevention effort of vital importance to infants and children is that of accident prevention. In 1979, the Maternal and Child Health program established accident and injury prevention as a high priority. Three projects of regional and national significance, targeted on injury prevention in childhood, were established with the State Health departments of California, Massachusetts, and Virginia. Working closely with both the private health sector as well as the public health agencies, the projects have provided significant baseline data on the epidemiology of childhood injuries, developed and tested a variety of intervention strategies, established some models for community-based injury prevention programs, and developed technical assistance tools and educational materials to translate the findings and results to health care providers in private practice as well as community health settings.

To assure transfer and application of these project experiences and results, three major activities have been undertaken. In cooperation with the Committee on Accident and Poison Prevention of the American Academy of Pediatrics, a nationwide program aimed at reducing childhood injuries and poisoning has been developed. This program is augmenting the AAP's "First Ride/Safe Ride" campaign stressing utilization of car safety carriers for infants. The injury prevention program launched on April 15, 1983 at the Academy's spring meeting is designed to assist pediatricians with accident prevention counseling and to identify families at greatest risk.

The Center for Disease Control, in cooperation with local health departments in Miami, Florida, and Pittsburgh, Pennsylvania, has also established two injury prevention demonstrations. These comprehensive community injury prevention demonstrations seek to reduce the disability and death caused by injuries to young children.

Health promotion and education contributes to improved health of babies and children. For example, CDC has worked closely with such private organizations as the National Center for Health Education and the American Lung Association to develop and encourage schools to adopt high quality school health education approaches in the primary grades. In nutrition, CDC monitors the nutritional status of high-risk children in 32 States and pregnant women in 18 States. This surveillance information allows States to target nutrition programs on the maternal and child nutritional problems they direct.

RESEARCH ACTIVITIES

Each Institute at the National Institutes of Health actively pursues both basic and applied research that shows promise of leading to methods of preventing or ameliorating diseases, with many new and exciting findings occuring in the areas of child health. However, the National Institute of Child Health and Human Development (NICHD) has the primary responsibility for research in childhood diseases.

Pregnancy, birth and the infant

A major and continuing priority of the NICHD is the reduction of the incidence of low birthweight infants. Because there is an excess of very low birthweight infants (under 1500 grams) in this country—a group which accounts for the higher perinatal mortality—the NICHD is seeking to identify biologic factors that predict women at risk for low birthweight infants, develop understanding and strategies for preventing maternal behavior that adversely affects fetal growth, describe the events precipitating labor, and finding ways of stopping premature labor.

A noteworthy recent finding is the first report of a substance produced by the fetus that signals the onset of uterine contractions. Since there is suggestive evidence that bacteria may initiate labor through a similar mechanism, NICHD has initiated a clinical trail of treatment of women with apparently minor infections of the maternal genito-urinary tract in hopes of determining if treatment of these infections will prevent premature labor. In addition, the District of Columbia, in conjunction with NICHD, is beginning an intervention trial to ascertain whether the totality of good early prenatal care, nutrition and the reduction of other fetal risk factors will reduce the percentage of low birthweight infants in the District.

Researchers have used animal models to understand the maturation of the fetal lung and the synthesis of surfactant, a substance in the lung necessary to prevent the respiratory distress syndrome (RDS) of infants with its attendant disability and death. RDS affects some 40,000 infants a year. As a result of these studies, a test to predict lung maturity is available; we have a treatment to accelerate the synthesis of surfactant during the last stages of pregnancy; and human surfactant has been used recently in infants to treat RDS and prevent the disabling sequelae.

Our ability to promote the survival and normal growth of infants under two pounds results from research on nutrition, pulmonary physiology, and the metabolic needs of these infants. Much needs to be done here since surviving infants often are mentally retarded and have other disabilities.

The Institute has completed an eight-year major research study of the cause of the sudden infant death syndrome. No single biologic factor was identified. Those conditions associated with low birthweight, also identify infants susceptible to SIDS.

Nutrition

Through ultrasound research on animal models it has been shown that even minor protein deficiencies during fetal development can produce changes in behavior well after birth.

The shift in breast feeding from 25 percent in 1971 to 58 percent in 1981 has resulted from the publicity accorded the research findings that the constituents of human milk prevent disease and promote the well being of the infant.

Because the nutritional needs of the growing child and the psychologic and socioenvironmental factors that determine food preferences and eating habits in adult life have not been completely defined, NICHD is assessing food preferences in early childhood with the goals of promoting a healthy lifestyle with respect to nutrition.

Congenital defects

The 125,000 children born each year with major congenital defects mandate a major research effort in this area. Research is currently directed at vaccine development for cytomegalovirus (CMV), which is responsible for defects in about 5,000 infants yearly. Experimental models of congenital CMV disease are now available and experimental vaccines are being readied for testing. A clinical trial of one of these vaccines is under consideration.

Birth defects are three times more frequent in infants of diabetic women than in infants of normal women even if diabetes is well controlled after mid-pregnancy. NICHD is sponsoring a major clinical trial to determine whether careful control of diabetes before conception and during the first trimester, when the organs develop, will lower the incidence of birth defects.

Between weeks 4 and 9 of prenatal life is the period of maximum sensitivity to viral disease, poor nutrition, drugs, and toxic substances. NICHD research on enzymes that metabolize drugs and toxins has the potential of predicting those women whose infants are at greatest risk for fetal defects due to exogenous substances.

Mental retardation

The prevention of mental retardation has been a major goal of the NICHD. NICHD research has led to routine neonatal screening for congenital hypothyroidism. The condition is difficult to diagnose clinically during the first three months of life when treatment is necessary to prevent mental retardation. Appropriate replacement of thyroid hormone now prevents mental retardation due to congenital hypothyroidism in about 1,000 infants annually.

NICHD-funded research in the behavioral sciences has made it possible to assess central nervous system function very early in life. Thus, infants at risk for mental retardation can be identified and treated with specially devised stimulation programs to prevent some of the sequelae of mental retardation. Such programs are possible because of earlier NICHD-supported research showing that intelligence can be modified and that training programs can prevent some of the maladjustments of persons with mental retardation.

The major effort in prevention of mental retardation still lies in the realm of fundamental neurobiology. The orderly development of brain neurons, the mechanism by which appropriate neural interconnections occur, the metabolic needs of developing nerve cells, and the role of environmental substances and processes, are only a few of the research areas under intense investigation supported by NICHD.

Child development

The major concerns of NICHD in this broad area is to determine how biological, psychological, social, and environmental factors interact in the development of normal behavior and to identify those factors that prevent or interfere with such development.

The Institute supports investigators studying the development of risk-taking behavior in older children, including identification of psychosocial factors that lead to attitudes or behaviors in children that endanger health or safety. The preventive aspects of this research thrust are of high priority since accidents remain a major cause of morbidity and death in children. Equally important is the prevention of development of lifestyle behaviors such as smoking and alcohol and substance abuse, that have negative influences on lifelong health.

NICHD supports research into the development of learning and cognition, social and affective adjustment, and the factors that impede the acquisition of speech, language, and reading.

Examples of research in prevention and child health in other NIH Institutes are: vaccine development to prevent infant diarrhea; prevention of neonatal hepatitis; prevention of late sequelae of juvenile diabetes mellitus; development of a safer vaccine for pertussis (whooping cough); prevention of neonatal ocular infections, a cause of blindness; a test for gential herpes to prevent exposure of the newborn during delivery; development of methods of enzyme replacement in metabolic diseases associated with mental retardation; and research on prevention of tooth decay and periodontal disease.

I will now briefly describe some of the child health research conducted by the Alcohol, Drug Abuse, and Mental Health Administration.

ALCOHOL AND CHILD HEALTH

In the last decade studies have yielded clear and compelling evidence that alcohol consumption during pregnancy poses a significant risk for the unborn child—with consequences including increased spontenous abortion, decreased birth weight, major and minor birth defects, and mental retardation. Some of the effects occur in children of alcoholic mothers, and others occur in children whose mothers drink moderately during pregnancy.

In the United States, the incidence of the fetal alcohol syndrome (FAS)—a specific cluster of severe and irreversible abnormalities—is conservatively estimated at 1,800 to 2,400 births a year. It appears clear that the incidence of FAS in the U.S. is similar in magnitude to the incidence of Down syndrome and spina bifida; together, these constitute the leading known causes of birth defects with mental impairment. Of these, FAS is uniquely preventable. The incidence of a broad range of other adverse alcohol-related outcomes is many times higher.

It is clear that women who abuse alcohol during pregnancy place themselves and their offspring at a substantial risk for a wide range of adverse perinatal and neonatal occurrences and outcomes. Moderate drinking—for example, alcohol consumption at the level of two drinks per day—is associated with decreased birthweight and behavioral deficits. Increased spontaneous abortions have also been observed for women who report drinking one or two drinks per day. There is as yet no agreed upon definition of a safe level of alcohol consumption during pregnancy.

In addition, it has been demonstrated that alcohol readily enters breast milk and thus is transmitted to the nursing infant. Heavy alcohol consumption is known to decrease the mother's milk.

I want to emphasize two points, Mr. Chairman: (1) the deformities, retardation, learning disabilities, and other lesser manifestations of alcohol consumption on our offspring can be prevented, and (2) the effects on pregnancy of alcohol consumption are independent of other potentially confounding variables including nutrition, smoking, caffeine, and other drug use.

The Federal response to the knowledge we have gained over the last decade on the effect of alcohol consumption during pregnancy has consisted of (1) continued support of research, (2) vigorous public education, and (3) heightened professional education.

At the present time the National Institute on Alcohol Abuse and Alcoholism (NIAAA) is supporting 13 fetal alcohol research grants and anticipates funding future research on effects of binge drinking, mechanisms underlying adverse effects of alcohol on offspring, and long-rang development of children born to mothers who drank during pregancy.

NIAAA's public education efforts include the development of television, radio, and print materials on the fetal alcohol syndrome and alcohol-related birth defects, alcohol problems among women, and alcohol problems among youth. As a result of this media campaign, States are developing their own materials, conducting training programs, and initiating a number of other public education and prevention activities.

We have approached health care professionals to keep them abreast of the most recent knowledge in a variety of ways—among them, basic professional education, continuing education, professional journals, professional associations, and direct communication. A Surgeon General's Advisory on the risks of alcohol consumption during pregnancy was issued that summarized scientific knowledge about these risks and urged physicians and other health professionals to advise patients who are pregnant or considering pregnancy not to drink alcoholic beverages. The Advisory was published as the lead article in the FDA Drug Bulletin, which is distributed to almost one million physicians, medical students, dentists, and pharmacists.

Mental health

Over the past two decades the National Institute of Mental Health (NIMH) has supported a broad range of research related to understanding the etiology of mental illness and debilitating emotional problems. Some of these lines of research have led to the development of programs to demonstrate that specific and timely interventions could prevent emotional problems from occuring or reduce their debilitating effects when they do occur. Prevention programs are identified as those initiated at the earlies prossible time either in age or in onset of symptoms. Thus, many of those preventive intervention programs have conducted with infants and young children.

Recent research funded by NIMH has shown that the threat posed to congitive and effective development by prematurity can be greatly reduced by programs that emphasize crisis counseling for parents and facilitation of parent-infant contacts in the nursery. With these technique it has been shown that by one year no significant differences are shown between pre-term and full term infants.

Current research in the NIMH Intramural Research Program is refining technique to predict which infants in high risk families will be most vulnerable to mental deficits, as well as techniques most effective in preventing negative outcomes, particularly among infants with adolescent mothers.

Loss of parent through divorce has been shown to increase the incidence of chronic depression and dysfunction in children. The NIMH has in the past decade developed a number of programs for marital counseling aimed at resolving marital differences and/or helping parents deal with the problems their children encounter when parents divorce.

DISEASE PREVENTION ACTIVITIES

Let me now turn to other childhood disease prevention programs of our Centers for Disease Control (CDC).

Great strides have been made in preventing childhood diseases through immunization. During the last two years, record low numbers of measles, mumps, rubella, polio, diphtheria, and tetanus have been reported in this country. The opportunity for further advancement toward the elimination of rubella and its life threatening sequela, congenital rubella syndrome, is at hand. Vaccination strategies in the United States have prevented epidemics of rubella and should eliminate major congenital defects due to maternal rubella.

Diabetes in children

Diabetes affects over a half million women of childbearing age and 120,000 children under 20 years of age. In partnership with the States and other public and private organizations, CDC is involved in activities designed to prevent unnecessary disability and premature death from avoidable complications of diabetes. These include patient education for the juvenile diabetic; development of pre-pregnancy counseling programs for women; and the initiation of screening programs to reduce morbidity and mortality in the newborn through early identification, referral, and proper care of women who develop diabetes during pregnancy.

Dental diseases

Although tooth decay affects virtually every person in the United States, children are most vulnerable. The fluoridation of community water supplies is the most effective mechanism for prevention of dental caries. Drinking optimally fluoridated water from birth reduces dental caries by approximately two-thirds. CDC provides technical assistance to State and local health departments in initiating fluoridation programs and in assuring optimal levels of fluoridation in existing programs.

Tuberculosis in children—an indication of ongoing transmission in a community—continues to occur in the United States. A key concern is the fact that the tuberculosis incidence rate has failed to decline among children 0-14 years of age during the period 1976-1981. From 1981 to 1982 the overall number of cases decreased by 6.8 percent; however, at the present time we do not know if the number of cases has decreased among children. Congress appropriated funds in Fiscal Years 1982 and 1983 to assist States and large cities in dealing with these problems. These resources have been used primarily for the employment of outreach workers to deliver directly supervised therapy to patients—especially children—and to ensure that rapid examination and preventive therapy are provided to all close contacts of newly reported infections cases, again with special emphasis on children under 15 years of age.

Sexually transmitted diseases

Gonorrhea, syphilis, chlamydia, and herpes simplex virus (HSV) are considered the most important sexually transmitted diseases (STD) affecting children. In partnership with the States and other public and private organizations, CDC is involved in activities designed to reduce the risk of STD infection and related complications in this vulnerable group. By emphasizing proper prenatal care, first and third trimester serologic testing, and timely referral for examination of sexual partners to reduce syphilis transmission in the community, we have an opportunity to reverse the recent dramatic increase in the number of congenital syphilis cases under one year of age. CDC is currently developing a national neonatal herpes surveillance system to determine the extent of the problem and develop proper prevention strategies. Chlamydial infections surveillance will become a reality when technological advances lead to the development of a less costly laboratory diagnostic procedure.

CONCLUSION

The health of our children has never been better. But the prevention programs of the Public Health Service are still of highest priority. We must continue to promote the benefits of preventive measures and positive health practices. And we must continue to work together. I have faith that we are fully capable of even greater achievement in maternal, infant and child health. But reaching the goals we have set for 1990 requires the collective efforts of the entire public health community—at the local, State of Federal levels. Promoting and protecting the health of the newborn is not only our responsibility, it is also the best investment we can make in the future good health of the American people.

Pregnancy and Infant Health Objectives

IMPROVED HEALTH STATUS

a. By 1990, the National infant mortality rate (deaths for all babies up to one year of age) should be reduced to no more than 9 deaths per 1,000 live births. (In 1978, the infant mortality rate was 13.8 per 1,000 live births.)

b. By 1990, no county and no racial or ethnic group of the population (e.g., black, Hispanic, Indian) should have an infant mortality rate in excess of 12 deaths per 1,000 live births. (In 1978, the infant mortality rate for whites was 12.0 per 1,000 live births; for blacks 23.1 per 1,000 live births; American Indians 13.7 per 1,000 births; rate for Hispanics is not yet available separately.)

c. By 1990, the neonatal death rate (deaths for all infants up to 28 days old) should be reduced to no more than 6.5 deaths per 1,000 live births. (In 1978, the neonatal death rate was 9.5 per 1,000 live births.)

d. By 1990, the perinatal death rate should be reduced to no more than 5.5 per 1,000. (In 1977, the perinatal death rate was 15.4 per 1,000.)

e. By 1990, the maternal mortality rate should not exceed 5 per 100,000 live births for any county or for any enthnic group (e.g., black, Hispanic, American Indian). In 1978, the overall rate was 9.6—the rate for blacks was 25.0, the rate for whites was 6.4, the rate for American Indians was 12.1; the rate for Hispanics is not yet available separately.

f. By 1990, the incidence of neural tube defects should be reduced to 1.0 per 1,000 live births. (In 1979, the rate was 1.7 per 1,000.)

g. By 1990, Rhesus hemolytic disease of the newborn should be reduced to below a rate of 1.3 per 1,000 live births. (In 1977, the rate was 1.8 per 1,000.)

h. By 1990, the incidence of infants born with Fetal Alcohol Syndrome should be reduced by 25 percent. (In 1977, the rate was 1 per 2,000 births or approximately 1,650 cases.)

REDUCED RISK FACTORS

i. By 1990, low birth weight babies (2,500 grams and under) should constitute no more than 5 percent of all live births. (In 1978, the proportion was 7.0 percent of all births.)

j. By 1990, no county and no racial or ethnic group of the population (e.g., black, Hispanic, American Indian) should have a rate of low birth weight infants (prematurely born and small-for-age infants weighing less than 2,500 grams) that exceeds 9 percent of all live births. (In 1978, the rate for whites was about 5.9 percent, for Indians about 6.7 percent, and for blacks about 12.9 percent; rates for Hispanics are not yet separately available; rates for some other nations are 5 percent and less.)

k. By 1990, the majority of infants should leave hospitals in car safety carriers. (Baseline data unavailable.)

INCREASED PUBLIC/PROFESSIONAL AWARENESS

l. By 1990, 85 percent of women of childbearing age should be able to choose foods wisely (state special nutritional needs of pregnancy) and understand the hazards of smoking, alcohol, pharmaceutical products and other drugs during pregnancy and lactation. (Baseline data unavailable.)

IMPROVED SERVICES/PROTECTION

m. By 1990, virtually all women and infants should be served at levels appropriate to their need by a regionalized system of primary, sescondary and tertiary care for prenatal, maternal and perinatal health services. (In 1979, approximately 12 percent of births occurred in geographic areas served by such a system.)

n. By 1990, the proportion of women in any county or racial or ethnic groups (e.g., black, Hispanic, American Indian) who obtain no prenatal care during the first trimester of pregnancy should not exceed 10 percent. (In 1978, 40 percent of black mothers and 45 percent of American Indian mothers received no prenatal care during the first trimester; percent of Hispanics is unknown.)

o. By 1990, virtually all pregnant women at high risk of having a fetus with a condition diagnosable in utero, should have access to counseling and information or amniocentesis and prenatal diagnosis, as well as therapy as indicated. (In 1978, about 10 percent of women 35 and over received amniocentesis. Baseline data are unavailable for other high risk groups.)

p. By 1990, virtually all women who give birth should have appropriately-attended safe delivery, provided in ways acceptable to them and their families. (In 1977, less than .3 percent of births were unattended by a physician or midwife. Furthermore, of births which are attended by a physician or midwife, an unknown share are not considered satisfactory by the women or their families.)

q. By 1990, virtually all newborns should be provided neonatal screening for metabolic disorders for which effective and efficient tests and treatments are available (e.g., PKU and congenital hypothyroidism). (In 1978, about 75 percent of newborns were screened for PKU; about 3 percent were screened for hyppothyroidism in the early 1970s, with the rate now rapidly increasing.)

r. By 1990, virtually all infants should be able to participate in primary health care that includes well child care; growth development assessment; immunization; screening, diagnosis and treatment for conditions requiring special services; appropriate counseling regarding nutrition, automobile safety, and prevention of other accidents such as poisonings. (Baseline data unavailable.)

IMPROVED SURVEILLANCE/EVALUATION SYSTEMS

s. By 1990, a system should be in place for comprehensive and longitudinal assessment of the impact of a range of prenatal factors (e.g., maternal exposure to radiation, ultrasound, dramatic temperature change, toxic agents, smoking, use of alcohol or drugs, exercise, or stress) on infant and child physical and psychological development.

Mr. **LEHMAN**. For the benefit of those who just arrived among my colleagues, we will operate strictly under the 5-minute rule. I will ask 5 minutes of questions, I will switch to the ranking minority, and then back to the ranking majority, and back and forth. But I will wield a tight gavel so everyone will have a chance to ask a question.

My question to you is the information you gave us on infant mortality, while these goals are very worthwhile, still our goal for 1990, 7 years from now, is lower than the Japanese actual infant mortality rate 5 years ago. So I wonder if our goals are not set too low, and also about the fact that the goal for the minorities is not set for 9 but set for 12 percent per thousand.

Why should the goals for the minorities not be the same as for anyone else, instead of having a widening gap between the mainstream of our people as far as infant mortality is concerned and those children from minority groups? That is my question, and I am anxious to hear your answer.

Dr. **BRANDT**. Well, I certainly would agree with both of your assumptions, Mr. Chairman. I think that in fact we will achieve a lower infant mortality rate by 1990 than the defined goal. That goal was actually defined in the period 1978 to 1980. It seemed like a reasonable one at the time. I think, at the rate we are currently going, we will easily exceed that, overall infant mortality rate.

With respect to ethnic minorities, obviously our goal has to be ultimately to get everybody's risk down to the same level, and I have no concerns about that.

The issue that we don't understand at the present time is how we are going to accomplish that task. There is no question that it is a very bad situation, that black mothers have an infant mortality rate that is twice that of white mothers. We certainly intend to gain in our understanding of how to alter that.

Mr. **LEHMAN**. Thank you. On the Foreign Operations Subcommittee, in examining which nations need our foreign aid assistance, the baseline figure we go by, as much as anything, to deterine the standard of living in the country, is the infant mortality rate, and we don't want to become a developing nation in this country.

I thank you very much, and at this time I would yield to Mr. Bliley from Virginia.

Mr. **Bliley**. Thank you, Mr. Chairman.

Mr. **Lehman**. I would like to submit the rest of my questions for the record.

Dr. **Brandt**. Thank you very much.

[Question and responses appear at end of hearing record.]

Mr. **Bliley**. Dr. Brandt, I understand that the Center for Disease Control maintains statistics on certain key measurements of infants and children applying for WIC participation. Have these measurements shown any deterioration in the past year?

Dr. **Brandt**. I must admit that you have caught me, Mr. Bliley. Right now I am not sure I can answer that question. I will have to supply the answer for the record. I am not aware of any deterioration in the monitoring activity of CDC. To be precise, I would like to supply it for the record.

[Question and responses appear at end of hearing record.]

Mr. **Bliley**. That is all the questions I have.

Mr. **Lehman**. Mr. Miller.

Chairman **Miller**. Thank you very much for your testimony. My question refers to page 16 of your testimony, which discussed childhood immunization. You review the great strides that have been made during the last 2 years in substantially reducing rubella, polio, diptheria, yet you seem less positive about our efforts to eliminate rubella and its life-threatening sequelae, congenital rubella syndrome. What are we missing in regard to that problem?

Dr. **Brandt**. The basic issue at the present time in dealing with the congenital rubella syndrome, and in fact dealing with measles in this country, are people at the college-age years. During the seventies, when the immunization rates in this country fell to someplace between 50 and 60 percent, a number of children who were born during that period were not immunized. So we have a number of young women in the college-age group who are not now immunized against rubella. They clearly stand, therefore, the greatest risk of having a baby with congenital rubella syndrome.

Chairman **Miller**. Is there an effort in terms of outreach?

Dr. **Brandt**. We indeed are making great efforts towards immunizing these people. During this past year, as you know, this issue was brought home to the higher educational community when we had outbreaks of measles at several universities. All of those universities and many other schools are developing immunization programs that are aimed at trying to prevent this. We believe that we can in fact get the women who are not yet immunized against rubella——

Chairman **Miller**. Are we allocating sufficient resources to do that?

Dr. **Brandt**. I think in this issue, yes, sir, we have resources allocated to do that, and we are in fact——

Chairman **Miller**. Are they sufficient?

Dr. **Brandt**. I think they are sufficient, yes, sir.

Chairman **Miller**. Mr. Lehman raised the issue of black infant mortality rates and you suggested that you would accept as a goal a

12-percent rate. You stated that it is a question of understanding the problem. Is it a question of understanding, or is it a question of resources, given the complex nature of the reasons for that gap?

You testified as to the 10,000 black infants that died last year. If we were prepared to allocate the resources to that population, what is it we don't understand that would prevent us from getting to the root causes?

Dr. **Brandt**. Well, I think one of the things that we don't understand clearly is the mix of those factors that lead to low birthweight infants among the Black people. They have a higher proportion of low birthweight infants. Part of this we know is related to the increased incidence of teenage pregnancy among Black women. We have attempted, as you know, through the adolescent pregnancy program and through other means, to try to reduce that. It is hard at this point in time to be sure how successful that program is, but that is certainly aimed——

Chairman **Miller**. Let me suggest that in areas we do understand, like nutrition and early prenatal care, access for eligible mothers is a major problem. That is not too hard to understand. It may be insufficiency of neighborhood clinics, physicians, or health-care facilities. These aren't terribly hard to understand if we want to make them available. I am not suggesting we do or don't. If we want to allocate the resources, some of these problems can be overcome.

Dr. **Brandt**. Yes, sir. I think that we are striving to overcome these through the community health centers program; through those kinds of activities which are in fact being enhanced and being stressed through the national health service corps programs and others, we have attempted to reach those people who are at highest risk. I think we are attempting to increase and improve access all the time. But we still know from various studies carried out by the NICHD and others that, even with facilities, the use of those facilities by Black women who are pregnant is not adequate. Now, precisely why that is true is something that we don't understand.

Chairman **Miller**. I'm certain we will explore this in our hearing on teenage pregnancy. However, again, I wouldn't us to leave the impression that this threshold of care can't be overcome essentially because we don't know what to do.

I say this because there have been a number of studies done in black neighborhoods which show that unwanted pregnancies can be reduced, and birthweights raised. I hope you will stay for this afternoon's testimony, when representatives of public advocates and others will testify as to their concerns about the allocation of these resources.

Mr. **Lehman**. The Defense Department would call it the "window of vulnerability." The gentlelady from Nevada.

Mrs. **Vucanovich**. Thank you. I appreciate the opportunity of appearing today and certainly appreciate the panel being here.

With respect to low birthweight babies and infant mortality, I think it is important that this Prevention Task Force keep in mind strategies that will deal in a comprehensive way with the babies at risk, and this committee really needs a better understanding of the social problems that result in babies being born at risk.

Dr. Brandt, you have mentioned in your testimony that infant mortality rates have declined, and yet through media reports we have a feeling that there is a public perception that these rates are all on the rise. Is there any way you can address this contradiction for our committee?

Dr. **Brandt**. Well, I am well aware of the media reports that report that, and I think that the media reports are based upon a misunderstanding of the variability of infant mortality, or any other mortality rate. The smaller the population base, the greater variabilities one would see. So that although it is true that during the past decade, for example, the infant mortality rate in this country has fallen at a rate of about 4 percent per year overall, every year approximately 13 States show an increase in their infant mortality rate. And the reason for that is really a statistical aberration, not anything more.

Certainly, if one gets down to cities or even to neighborhoods, then the variability is going to increase rather dramatically. As a matter of fact, I happen to have a couple of charts that might illustrate that since I suspected it might come up.

This is a comparison, first, of two States, Michigan and Rhode Island. One of which, Michigan, has approximately 150,000 births per year, and Rhode Island having about 13,000 births per year. You can note that the rate in Michigan continues to fall rather consistently, although even in Michigan you will see several periods of time where the death rate does rise, while in Rhode Island there is great variability from year to year because the nominator is small. It's an arithmetic aspect.

I think, to pick out and say that over a short-term period, in a small population base you see an increase, is not something that you ignore. I think if babies are dying, you try to find out why they are dying and do something about it. But, on the other hand, it does not necessarily indicate that the overall trend is changing.

Mrs. **Vucanovich**. Thank you very much.

I would like to ask the chairman if my opening statement can be made part of the record.

Mr. **Lehman**. Without objection.

[Opening Statement of Hon. Barbara Vucanovich follows:]

OPENING STATEMENT OF HON. BARBARA VUCANOVICH, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEVADA

Mr. Chairman, I thank you for providing me with this opportunity to speak at the first hearing of the Prevention Task Force and the Select Committee on Children, Youth and Families. I welcome those who have come here today to testify and I look forward to having the benefit of your expertise.

I would like to add that I am disappointed that the Minority was not allowed to call some of its own witnesses for this first hearing, but it is my understanding that this has been resolved for future Select Committee hearings. It is my strong feeling that this right to call witnesses should be adhered to in the future.

With respect to low birthweight babies and infant mortality, I believe it is important that this Prevention Task Force keep in mind strategies that will deal in a comprehensive way with the babies at risk. This Committee needs a better understanding of the social problems that result in babies being born at risk. I would hope that this will be addressed in the testimony to be heard today.

Mr. **Lehman**. Mr. Weiss.

Mr. **Weiss**. Thank you very much, Mr. Chairman.

Dr. Brandt, I am sure that it is not intended that way, but as I listened to your testimony and I read it, I get a sense of self-satisfaction with the state of infant and child well-being in this country, which I am sure that you don't want to project.

Dr. **Brandt**. Well, I am sorry that—I have a feeling of satisfaction that progress is being made. I am not satisfied that we are there.

Mr. **Weiss**. Let me ask you some specific questions.

Dr. **Brandt**. By the way, that is why, of course, we have adopted these goals and why we are working so hard to try to implement them.

Mr. **Weiss**. The 12.0 infant mortality rate for the population at large, and the 21.4 for the black community, how does that fit in in relation to the rest of the world?

Dr. **Brandt**. Well, I don't know, the 1983 ranking, but we are certainly not in the top 10 yet.

Mr. **Weiss**. Right. Now, what kind of progress has been made in the black community, over the course of the last 5 years, in the reduction of the mortality rate?

Dr. **Brandt**. It has been coming down at a rate of somewhat less than that of the white population, but it's approximately 3.5 percent per year.

Mr. **Weiss**. And do you see any connection between the goals that you have to meet and the amount of resources that this administration and future administrations are going to have to commit to that effort?

Dr. **Brandt**. Well, I think that in fact we are a long way from not having to commit reasonable amounts of resources to this problem.

Mr. **Weiss**. Say that again.

Dr. **Brandt**. I think we are a long way from achieving the goals that would say that we no longer have to commit resources to this problem.

Mr. **Weiss**. Say that positively. What do you think has to be done in order to meet the goal?

Dr. **Brandt**. Wait a second.

Mr. **Weiss**. You said we are a long way from it. OK, I agree. Now tell me, what do you think has to be done by way of resource commitment to meet the goals that you have outlined in your testimony?

Dr. **Brandt**. Well, I think, in the first place—Mr. Miller might disagree with me—I think in the first place we need to understand what to do before we try to do something. In fact, one of the major causes of low birthweight infants in this country is prematurity. We don't know why people go into premature labor.

Mr. **Weiss**. Would you agree that the Women's Infant Children's food program has helped to in fact produce healthier babies, healthier mothers, cut back on malnutrition, cut back on some of the other problems which in fact would cause problems in birth delivery and in survival of infants?

Dr. **Brandt**. I am sure that improved nutrition, improved prenatal care, and so forth, have all contributed.

Mr. **Weiss**. Do you think that that program, for example, ought to be accelerated as far as resources are concerned, or do you think that we have done enough and we can sort of stay on hold at this point?

Dr. BRANDT. At this point in time, I am prepared to talk to you about what the Public Health Service is doing. I really don't have the details about the program you are talking about in order to tell you whether it ought to be accelerated or not.

I think in fact the program is making strides and is moving to accomplish some of those goals. I think we can't forget that one of the major reasons for that, that our infant mortality rate is coming down, is because of the medical care side of the issue. We can't forget that, although I admit they are very expensive, that better transportation, better care of high-risk mothers during labor and——

Mr. WEISS. You don't think that prevention is really a major way of——

Dr. BRANDT. I think prevention is the major way. I don't think at the present time, however, that it has been the major contributor, no. I think it is the major way to go, and I have no question about that. I think at this point in time that we probably have gone almost as far as we can go in further reduction by improved care during labor and after delivery.

Mr. WEISS. You have spoken, of course, in your testimony about the healthy mothers, healthy babies campaign. Are you satisfied that when women are encouraged to participate in that program for prenatal care, that the level of services is sufficient, so that people who want to participate can do so?

Dr. BRANDT. I suspect that the level of available care is probably not at the point where every possible person can get complete care, although I still would maintain that we have capacity out there that is not yet being utilized. One of the reasons that we would like to—one of the reasons for the healthy mothers, healthy babies campaign is, again, an educational process to try to encourage people to make use of the facilities, make use of the prenatal care that is available.

Mr. WEISS. So that the problem is not that it doesn't exist, it's that people aren't using it, as far as you are concerned?

Dr. BRANDT. As far as I am concerned, it is a dual problem, but I think we can't just accept the fact, we can't ignore the fact that we still have to encourage people to make use of the medical care in addition to having it available.

Mr. WEISS. Thank you very much.

Mr. LEHMAN. Thank you. The gentlelady from Connecticut.

Mrs. JOHNSON. No questions.

Mr. LEHMAN. If you have any questions, you may submit them for the record. The gentlelady from Louisiana, Mrs. Boggs.

Mrs. BOGGS. Thank you. Thank you and all of you for being with us.

I would like to pursue a little bit the serious impact of teenage pregnancy on the physical health and the mental health of the teenage mother and her offspring, and the Public Health Service programs for trying to reduce the incidence of teenage pregnancy and the counseling of pregnant teenagers during the critical pre- and peri- and postnatal periods.

Do you think you have sufficient programs, or do you need expanded programs in regards to the counseling at these various stages of teenage pregnancy?

Dr. **Brandt**. Under the Adolescent Family life program, which was passed by Congress a year or so ago, we have initiated a number of demonstration projects around the country. The demonstration projects are aimed at attempting to demonstrate and measure how one goes about accomplishing precisely what you are talking about, as well as counseling which might prevent teenagers from becoming pregnant in the first place, which it seems to me is the appropriate way to go.

I think when we have gained that kind of information, plus working with the professional groups, that we will begin to make some significant strides in this area.

Mrs. **Boggs**. There have, of course, been findings that teenage mothers who receive parental and social support are beginning—in the first trimester of their pregnancy, the children are no more at risk than other children. But these findings need replication?

Dr. **Brandt**. Yes.

Mrs. **Boggs**. I wonder what programs the Public Health Service has that are aimed at replicating these findings and at making certain that the information is readily available to your whole network of doctors and paramedics and social services.

Dr. **Brandt**. With respect to teenage pregnancy, we have a number of projects underway. Some of these include teenage mothers who tend to have a higher risk of premature labor. We are trying to not only understand the cause so that we can prevent it, but also a method of intervening to stop premature labor.

Second, we know very well that smoking and drinking during pregnancy has much more significant effect in teenagers than it does in older women. Or at least the evidence would indicate that. And we certainly have projects underway to look at those.

The demonstration projects under the Adolescent Family life program will also provide us the kind of information that you are asking for, and we will, of course, make that readily available throughout the network.

Mrs. **Boggs**. I am glad you mentioned the alcoholic problem because, of course, fetal alcohol syndrome, as you pointed out in your testimony, is a very serious and difficult syndrome that we are all experiencing—1,800 to 2,400 births a year, at least.

Dr. **Brandt**. That is the full-blown syndrome, not the minor difficulties that come from greater numbers.

Mrs. **Boggs**. But also, as you pointed out, it is uniquely preventable?

Dr. **Brandt**. Yes.

Mrs. **Boggs**. I notice that you have a very ambitious program to try to notify everyone about the difficulties associated with drinking during pregnancy. Is this an emphasis on your teenage programs as well?

Dr. **Brandt**. Yes, and we have, as you know, underway a fairly extensive campaign on teenage drinking, which focuses on driving, because that does account for roughly half the deaths of teenagers in this country, from drinking and driving. This is built around groups, particularly students, called SADD, Students Against Drunk Driving, which is, very, very impressive.

We had a nationwide meeting not long ago with the students involved a very, very impressive group of young people who also are very aggressive. As a part of that, of course, we hope to get across the message to teenagers about the problem of drinking and pregnancy. So I think that we are attempting in most every way that I know of to get that message out and get it across with respect to pregnancy, not only to teenagers but to women of all ages.

Mrs. **Boggs**. The program of preventing drunken driving is excellent and it is something that is very appealing. I think it is a very splendid sort of handle to place upon the teenage pregnancy and drinking. It can be so easily related through teenage groups, as you have been able to focus your program against drunken driving among teenagers through the teenage groups themselves. They should feel very responsible about teenage pregnancy, and I would hope that you would stress that along with the drunken driving.

Thank you, Mr. Chairman.

Mr. **Lehman**. Before going to the gentleman from Texas, Mr. Leland, I wonder if you would like to correct or look over an expression you used called college-age women, because in the record it would indicate much younger than the average age of the largest university in my district, where the average age of a college woman is 32.

Dr. **Brandt**. I was talking about somewhat younger women.

Mr. **Lehman**. I think there is no such thing as a college-aged woman anymore.

Dr. **Brandt**. Yes, I guess I should say, then, 18 to 24.

Mr. **Lehman**. Without objection, the record may be changed.

Mr. Leland.

Mr. **Leland**. Thank you very much, Mr. Chairman. I have an opening statement I would like to submit for the record, if I can, without objection.

[Opening statement of Hon. Mickey Leland follows:]

Opening Statement of Hon. Mickey Leland, a Representative in Congress from the State of Texas

Mr. Chairman, members of the committee, we are fortunate today to be able to hear from three panels of distinguished experts on the important issues concerning prevention strategies for healthy babies and children. During these uncertain economic times we are now experiencing which has led to record high unemployment, we need only look to the health of our children to confirm the severity of our situation. It is no longer uncommon to hear about incidents of repeated abuse and neglect of children nation-wide. It is tragic to learn that these figures have doubled in just one year. In the area of child support, it is estimated only one-third of the women heads of household with children under 21 receive child support payments from absent fathers.

While we hear that the "general" condition, environment or services for infants and children have improved, I am saddened and angered by the consistent inequities unique to minorities. Blacks and Hispanics have faired much worse in every category—including higher percentage of unemployment; lower median family income which accounts for more minority children living in poverty; lower mean annual child support payments; lower education achievement scores in reading and math; lowest percentage likely to receive prenatal care; highest mortality rate; highest incidents of deaths of homicides; highest percentage of illegitimate children. . . I could go on, but I think we get the point.

It is high time we examine and re-evaluate the role our government programs play as they relate to the status of our children.

I particularly appreciate this opportunity to address the increasing incidences of teenage pregnancy. This is a major source of concern for all of us—social service providers, policy-makers as well as the public at-large. With over 1.5 million teenage pregnancies in 1980 alone—up more than half a million from the late 1970's—this is indeed a critical area in which we should be concentrating our resources.

In most cases, teenage pregnancy poses significant risks for many, including physical problems for both mother and child, the probable interruption of education for one or both parents, inevitable low-paying employment, and, in most cases, eventual welfare dependency.

It is essential that we address the Federal responsibility in providing effective preventive support systems and encouragement to local agencies and governments at this time. During these unpredictable times, we must be able to assure every individual seeking help, that their voice will be heard and action will be taken to lessen the burden and pain.

Mr. **Leland**. I also have several questions I would like to ask Dr. Brandt, but I know the time won't permit. I would like to also submit them for future response.

Dr. Brandt, as you know, I represent Houston. You were there for, I guess, many, many years, and you understand Houston better than most people from your vantage point.

I am particularly concerned about the questions that were raised by both the gentleman from California, Mr. Miller, and also initially by the gentleman from Florida, the chairman. In my district, I have census tracts that have horrendous statistics as far as infant mortality is concerned, and yet Houston is a rather affluent, if not the most affluent city in the country.

You have alluded to the fact that you have not determined exactly how it is that this problem exists and how you attack the problem. But when I first came to Congress I established an infant mortality task force in Houston and we arrived at the conclusion, in conjunction with the Health Subcommittee on which I served, of the Energy and Commerce Committee. We arrived at the conclusion that one of the real problems was the fact that the system does not provide any real outreach.

The only real outreach was in fact the WIC program, and this administration has cut the WIC program considerably. We have no real resources to avail ourselves of in Houston to provide for any outreach.

Don't you agree that indeed outreach has to be effected in order that we can change these statistics, because, in fact, in those census tracts is a fact that I would like to admit to, because it's somewhat embarrassing, but the fact is that I have a rather uninformed community that does not understand the nuances of the problem and therefore prevention cannot prevail because nobody is educating the people in the community because there is virtually no outreach.

Don't you agree that that could be a possible solution to at least a portion of the problem?

Dr. **Brandt**. Absolutely. I think that the outreach programs and, of course, the conclusion of your Infant Mortality Task Force certainly came—to the same basic conclusion. I think there have been some steps taken, as you well know, in Houston to try to accomplish that.

We must carry out an educational campaign that is aimed at attempting to get into the areas where there are high rates of high-risk pregnancies. The Healthy Mothers, Healthy Babies Coalition, which is now becoming national and becoming involved at the local levels, is aimed precisely at trying to accomplish that step.

Mr. LELAND. How many black people are involved in that program?

Dr. BRANDT. Well, a fair number. The National Medical Association is involved. I have a list of all of the organizations. I am not dredging it up out of my memory at this moment. But there are a fair number and in fact most of the educational materials have been gone over, reviewed, and approved by the National Medical Association and other Black organizations, since a lot of the emphasis of the Healthy Mothers, Healthy Babies Coalition is aimed at minority populations.

Mr. LELAND. Doctor, several months ago it was learned, much to my distress, as well as many of my colleagues, that the Adolescent Family Life Act administrators had not awarded the grants to minority organizations.

Dr. BRANDT. That is not true.

Mr. LELAND. Well, can you——

Dr. BRANDT. I will be happy to provide you with the list of the minority, principally black organizations, to which those grants have been awarded. Now, as you know, we are going largely by what the applicants say they are, as we don't have registration but there are several awarded to grantees who are black and who are intending to serve principally black communities. I will be more than happy to send you a list of those.

Mr. LELAND. To give some real clarification as to what we are talking about, can you give me the statistics on infant mortality rates in the white community, infant mortality rates in the black community, and infant mortality rates in the Hispanic community?

Dr. BRANDT. Yes, sir, we can give them to you up to 1980.

Mr. LELAND. Do you have them now?

Dr. BRANDT. I think we have the Black and the white, but I don't have the Hispanic, I don't believe. This only has 1978, but the white rate at that time was 11.4. The Black rate was 21.8.

Mr. LELAND. Do you have the statistics on Asian or Hispanic Americans?

Dr. BRANDT. I don't have it here, no, but we certainly have all of that data.

Here we go. That is black and white. It does not include Hispanics or Asian Americans, all of which we have and will be happy to supply to you.

[Questions and responses appear at end of hearing record.]

Mr. LELAND. I think my time has run out, but I am really concerned about this problem. I think that is why there is such an abundance of questions on this particular issue. But you seem to place a low priority, in what I heard you say—maybe it's a misinterpretation, but you seem to place a low priority on prevention.

I heard you say that, yes, we ought to work on prevention. The question from the gentleman from New York, Mr. Weiss, elicited a response from you that said, yes, we ought to emphasize prevention but that doesn't necessarily mean that prevention will solve the problem.

Dr. BRANDT. No, let me make myself very clear about that, because I spent my life in preventive medicine and I can guarantee you that I think prevention is the most important approach to the handling of this problem or any other disease problem in our society.

I think we, at the same time, have to be honest and recognize that the major impact on the drop in infant mortality in the past decade in this country has been the adequacy of and advances in medical care at the end of the pregnancy. The development of the neonatal intensive care, regionalized transportation systems, those are the things that have had the major impact. It is not the only impact——

Mr. **Leland**. Even at that, doctor, the fact of the matter is that black people tend not to have the same accessibility as do other people.

Dr. **Brandt**. That is why——

Mr. **Leland**. Is there an emphasis on the part of your administration, in what you are doing, on trying to provide that accessibility?

Dr. **Brandt**. Yes, sir. I think we have been working pretty hard to try to improve the accessibility and to improve the awareness of the things that are available. I want to be very clear that our primary emphasis is going to be on, and is on, prevention of these problems. That is where we are headed.

But I think that we have to also, as a part of that totality, do precisely what you found in Houston, what other people have found around the country, and that is the kind of outreach programs that make people aware of these possibilities. It is not going to work without this. That is one of the reasons why we have attempted to increase that awareness to the extent that we possibly can, and I think we will continue to do so.

Mr. **Leland**. Thank you, Mr. Chairman.

Chairman **Miller**. Again, I would hope that somebody from your office will be here this afternoon as we'll see studies which suggest that in fact the gap between black and white infant mortality was closer in 1950 than it is today, and that in the last 3 years it has gone from being 70 percent higher than whites to being 80 percent higher than whites.

I think it is important at this point that the committee be aware that there will be testimony this afternoon suggesting that the problem is in fact increasing in terms of the gap.

Ms. **Mikulski**. Thank you very much. Dr. Brandt and gentlemen, it's a pleasure to welcome you to this important committee.

I would like to just refresh you quickly on the background of this committee, which then will take me to the reason for asking some of the questions I would like to have answered.

We found within the Congress of the United States, at least within the House of Representatives, Dr. Brandt, that the needs of children, young people, and families, were spread over 13 different committees and subcommittees. There was no one-stop shop in the Congress to take a coordinated approach for looking at the needs of children and their families.

Therefore, we had no way of understanding whether or not programs were meeting the needs of children. In nutrition, for example, WIC is over in the Waxman committee, food stamps is in Agriculture, school lunches and breakfasts are over in Education and

Labor, and we had no single place where we could examine these programs together nor could we see if we were getting a dollar's worth of services for a dollar's worth of taxes, which is the reason for establishing this committee.

As I sit here listening to both the testimony and some of the questions, I wonder if there is any mechanism at the Department of HHS that is a one-stop shop that is looking at the needs of maternal and child health care. Is there?

Dr. **Brandt**. Yes, there is. There are two mechanisms. In the first place, under our prevention campaign, we have organized task forces who in fact meet regularly and for which regular progress reports and activities are published, and I would be happy to submit to you the most recent for the record, if you would like, the most recent progress report on the pregnancy and infant health objectives which are sitting right here, and which are published and are available and indicate that. That is one mechanism.

The second mechanism is through my office and the meetings and activities that we have set up between me and the Office of Human Development Services and the Health Care Financing Administration, where we attempt to look at not only maternal and child health but other programs that cut across these lines. So I think we have set up a number of ways to do it.

In addition, of course, we have the maternal and child health division that is located in Dr. Graham's agency, the Health Resources and Services Administration, and they have the principal responsibility for pulling together all of the medical and other aspects of maternal and child health.

So that I think we do have mechanisms in place for trying to coordinate and to get an overall look at this activity.

Ms. **Mikulski**. As I listen to your report on how the needs of young children are met, I wonder what programs under medicaid deal with the problems of maternity and early childhood health. Do you feel, given the current state of medicaid, those programs are adequate?

Dr. **Brandt**. I would like to submit, at least the first part of that for the record, rather than to try to get into it at the moment. I think the question of the adequacy, I guess is the issue of trying to talk about roughly 57 States, territories, and the District of Columbia, since each of them has somewhat different programs, and the question in my mind is that in some States those programs are quite adequate, but that is, as you know, a program that is largely determined by State activities.

One of the activities, of course, we have been concerned with, is to try to work with States as they put together a total program that involves medicaid, block grants, other kinds of activities, so that they can meet the needs of their people. Therefore simply pulling one program out and comparing it from State to State doesn't necessarily give you the whole picture.

Ms. **Mikulski**. That leads to some other questions. One of the things we hope to achieve here will be some recommendations for legislation. I think one natural question is whether or not there should be statutorily defined minimum programs for maternal and child health care within medicaid legislation. I am not asking you to answer that now, but I am trying to see, what does medicaid do at this stage of childhood development.

Second, what are the categorical programs that meet the needs of mothers and children at this stage?

Dr. **Brandt**. Probably the major one at this stage is the community health centers program, which certainly provides the medical care to large numbers of eligible mothers and children. The immunization program is another one that is categorical, and that meets those needs. Then, other than get into specifically risk areas, such as our diabetes and TB programs, through CDC, those sorts of categorical programs certainly cut across and through vast aspects of maternal and child health. But the basic one, there are several also in the division, the so-called projects of regional and national significance, certainly is another program that is aimed at categorical and directed specifically toward maternal and child health.

Ms. **Mikulski**. What about block grants?

Dr. **Brandt**. What about them?

Ms. **Mikulski**. Well, are there special programs, are there block grants devoted to maternity and child health, or are the concerns of maternity and child health mixed in with the other block grants and other grants and therefore have to compete?

Dr. **Brandt**. There is a maternal and child health block grant.

Ms. **Mikulski**. What does that do?

Dr. **Brandt**. That does what the States want it to do.

Ms. **Mikulski**. Are there minimum standards or minimum programmatic criteria that States have to meet to qualify for the block grant?

Dr. **Brandt**. The only qualifications that I am aware of are obviously discrimination qualifications, the fact it has to be used in maternal and child health programs. Dr. Hutchins, who administers that, may have something to add to that.

Dr. **Hutchins**. The only other part is, there is a report of intended expenditures which comes in, which tells what the States are going to spend the money on the programs after they have set goals and objectives for the program.

Ms. **Mikulski**. Doctor, in the block grant for maternity and child health care, do we say it has to include certain prenatal care, certain immunization, certain follow-up within certain times afer birth? for instance, Does every child get some type of examination x numbers of weeks after birth and is followed for x numbers of months?

Dr. **Brandt**. The answer is no, there are no such requirements. The most common expenditures, however, under the block grants are, prenatal care; child health, especially under 5 years, including the well child clinics, pediatric clinics, and that sort of thing; care for handicapped and chronically ill children, which is the third most common expenditure under that block grant program.

Our view about that, as you know—you and I talked about this in another circumstance—is that we believe that the States ought to put together the total plan that they have to take care of the people of their State and that therefore we put the minimum requirements on the States to try to specify what the exact nature and content of those programs would be.

I think this is an indication that they would certainly follow the guidelines that we were all setting and all our people would probably write. Being neither of those, I would prefer to leave it up to the doctors that are out there delivering the care.

Ms. MIKULSKI. I am not going to go over every State, Mr. Chairman. I think Dr. Brandt's answers to the question indicate a need for both this committee and HHS to gather information about the situation in the States.

I feel that the committee needs some type of flow chart to illustrate which programs affect both young children and their mothers. We need to examine block grants and medicaid categorically. We need to know what each State does with its block grant and medicaid money. This way we can decide on courses of action on this issue.

Obviously, each State uses its funds differently. I don't think we have the administrative mechanism to evaluate the adequacy of these programs or the adequacy of funding.

So I would ask the committee, and ask unanimous consent of the committee, that the staff be directed to work with Dr. Brandt to develop such a flow chart.

Mr. LEHMAN. Without objection.

Chairman MILLER. We will take it under advisement. That is a big order. I think you are on the right track.

Mr. LEHMAN. I know what happened in Florida. When we passed legislation with some strings attached, the Florida block grant program did not want to live up to it. They just wanted to spread the money around and water down all kinds of programs. If we pass legislation here, and it is not implemented as intended by the block grant State programs, then we might as well be pouring money down a rathole. That is more or less the idea you were trying to get to.

Ms. MIKULSKI. I want to know what it is we are supposed to be providing and then go to whether it is working.

Mr. ROWLAND. I have a question with reference to immunization, smallpox vaccinations are no longer used. You mentioned pertussis in your statement as being a problem. There may be some relation between pertussis and some problems we have now, such as autism. Are there any statistics now available that might tell us just what the relationship may be and what is taking place in that particular area?

Dr. BRANDT. There are some claims regarding the pertussis vaccine. What I was trying to say is that we recognize that the pertussis vaccine is not perfect and that we are working toward development of a safer vaccine. The major claims that are made have to do with seizure disorders in children following receipt of pertussis vaccine.

That is very difficult to evaluate because children at that stage, roughly 6 months of age, tend to have seizure disorders of an unexplained nature, not uncommonly. So whether or not it would just happen to be inadvertently associated in time or directly associated isn't clear. In my judgment, I think it is not clear at all. However, even if one accepts that all of these are clearly related to the vaccine, the vaccine is still the way to go because whooping cough is a killer and whopping cough results in much more serious problems than the vaccine if one accepts all of the side effects as being valid.

So, our efforts are principally aimed at trying to see if we can find a vaccine that is purer than the one that we currently use. There are several models around that we are working on, but I certainly want it to be clearly understood that I would immunize any children with current pertussis vaccine without even thinking about it. I would also point out that some of the scare tactics that have been used in recent years have resulted, certainly, in a reduction of early vaccination and led to marked increases in the disease. It is truly unfortunate that when the media talks about pertussis vaccine they don't show a picture of a child with whooping cough. One only needs to hear that once, and I can remember very well as a resident hearing it too many times. I don't want to hear it again.

Mr. ROWLAND. Are you aware that there may possibly be some relationship between immunization and IDP and mental disorders in children?

Dr. BRANDT. Yes, sir, I am aware that association has been claimed. But, again, as I say, it's difficult to separate those issues out.

Mr. ROWLAND. Thank you, Mr. Chairman.

Mr. LEHMAN. Mr. Wolf.

Mr. WOLF. No questions, thank you.

Mr. LEHMAN. Mr. Levin.

Mr. LEVIN. There has been reference here to the MCH block grants. Let me ask you first, what proportion of the budget that relates to children, say, is in prevention?

Dr. BRANDT. I really don't have that figure right on the top of my head. I would have to provide it to you. It's a fair amount, if you count the immunization program, TB prevention programs, et cetera. Are you talking about specifically in the block grant, how much is it used?

Mr. LEVIN. No, but talking today about prevention strategies, I think it would be helpful for the committee to know what proportions and parts of the budgeting go for prevention strategies or prevention programs.

Dr. BRANDT. Well, we would be pleased to provide that to you.

Mr. LEVIN. Do you have any idea whether those monies in that proportion or those proportions have gone up or down in the last few years?

Dr. BRANDT. They have gone up.

Mr. LEVIN. If you could provide to the committee those figures, it would be helpful.

Dr. BRANDT. All right.

Mr. LEVIN. Let me ask you in reference to the MCH block grant, because you have made reference to it, for example, in relation to the infant mortality. What has been the record of your request for funds for MCH block grant?

Dr. BRANDT. Congress has——

Mr. LEVIN. Your request.

Dr. BRANDT. The record of them?

Mr. LEVIN. What have you requested during the years of the block grant?

Dr. **Brandt**. Well, we requested $316 million, I guess it was in 1982 and 1983.

Mr. **Levin**. And how about for 1984?

Dr. **Brandt**. $373 million.

Mr. **Levin**. $416 million in 1982?

Dr. **Brandt**. 1983.

Mr. **Levin**. $316 million in 1983?

Dr. **Brandt**. $373 million in 1984.

Mr. **Levin**. Regarding infant mortality, let me just return to it briefly, because in the draft of your testimony I understand—I wasn't here, I am sorry, for your actual testimony itself, but I understand—that you, in your testimony, very much reflect the draft statement that I saw.

Dr. **Brandt**. Yes, sir.

Mr. **Levin**. You indicated the goal for reduction of infant mortality to be 9 per 1,000 by 1990. In parts of southeast Michigan, as you know, there is evidence that the levels have been going up. How are you responding specifically? If you are talking about a goal in 1990 of a substantial reduction, and there is some evidence of an increase in these times, how do you measure this and what are you doing about it?

Dr. **Brandt**. Well, I think, Mr. Levin, that in the first place we work with and provide whatever assistance we can to the State health officer of Michigan. It so happens we have a chart of Michigan that we might take a look at, which I think illustrates part of the dilemma, because there was a great deal of publicity a year ago about Michigan's infant mortality rate going up.

I think you will notice the dark line. Michigan is consistently coming down, but in individual years it does tend to go up. That is largely a factor of both, the number of births, the denominator, and the number, clearly, of deaths, in the numerator, which can fluctuate somewhat. But you will notice that, even though, in 1981 that rate tended to go up. It is back down in 1982 below the 1980 levels. In early 1983 it would indicate that same trend is continuing.

Mr. **Levin**. Is that a uniform trend throughout the State?

Dr. **Brandt**. No; of course not.

Mr. **Levin**. I am talking about the trend up and down.

Dr. **Brandt**. The trend up and down, again, yes, that tends to vary even in small sections. It will tend to fluctuate, but in some parts of cities and States in the country the infant mortality rate tends to come down to a lower level, obviously, than it does in other parts. The precise reasons for that vary considerably, depending upon the population and the health care services available, and other services that are available to it. I don't happen to know about southeast Michigan specifically, but I think that we are available and willing and able to work with any of the State health officers, either locally or, any of the health officers, locally or State, to try to assist them in solving the specific problem they might have.

Mr. **Levin**. So, you haven't seen any data on infant mortality in any parts of Michigan that are disaggregated a bit, that are of any concern to you in terms of trend?

Dr. **Brandt**. I have not seen any. I think all of the data from Michigan and other places is of concern to us in that it is not down as low as it ought to be, and so that the answer to your question is that I have seen data that is of concern to me in Michigan and in other States as well.

Mr. **Levin**. One last question. Let me just go back for a minute to the MCH block grant program because the information that I have received from Michigan as part of the program relates to the level of those funds. What was the first year of MCH block grants?

Dr. **Brandt**. 1982.

Mr. **Levin**. You know you mentioned the figure $316 million. Do you know what the figure was for 1981 and 1980 for the program that has become part of the block grant program in 1982?

Dr. **Brandt**. $363 million.

Mr. **Levin**. What was the level in 1981?

Dr. **Brandt**. That was the level in 1981.

Mr. **Levin**. So there was a reduction from 1981 to 1982 from $363 million to $316 million?

Dr. **Brandt**. That is correct.

Mr. **Levin**. Let me ask you how, with that kind of reduction, you can use the MCH block grant program as major evidence of a commitment to get at prevention programs.

Dr. **Brandt**. Well, I wasn't aware that I was, but——

Mr. **Levin**. I thought you had raised——

Dr. **Brandt**. What I was saying is that one has to look at the totality of the efforts going on in any particular State. It is not really possible to take State expenditures on, let's say, the MCH block and look at that totally independent of immunization programs that are underway, community health center programs that are underway, other kinds of efforts that are underway, by either the State or local government or other health professions in that area, unless you can see the totality and medicaid activities as well, because all of those contribute to the prevention activities. So, that I am trying to give the overall view of the total Federal effort that is going on.

I am not including enormous amounts of funding and other programs that are underway at the State and at the local level. Many cities have very well organized programs and put large amounts of funds and large numbers of people into them. Other States do the same thing. The concept underlying the block grant was to allow the States to develop the programs totally involving their own resources and their own efforts as well as those of the Federal rather than to have the Federal Government come in and lay over a different kind of program than was underway at the State. I think one, looking at Michigan or looking at my own home State of Texas, will see that this enormous amount is going on that is really unrelated to the Federal efforts.

What we have done I think with the block grants is to augment those local efforts in a way that allows them to be more complete and more efficient than they were before.

Mr. **Levin**. Let me ask if you would then submit at your convenience, take Michigan and take the totality and let me know how you think it adds up, because as you know, within Michigan and other States, there were some severe budget cuts in recent years and I fully understand the MCH block grant was one piece of it, and you urge we look at the totality, and I would like to see the totality as you see it.

Dr. **Brandt**. We can certainly provide you with the totality of the Federal Government. We will try to get hold of the local people in Michigan to get whatever information we can about State and local contributions.

Mr. **Levin**. I appreciate that.

Mr. **Lehman**. Mrs. Johnson.

Mrs. **Johnson**. Thank you very much.

Since I came in right after your testimony, I did not have a chance to review it. You do point out in your testimony, however, that even minor protein deficiencies during fetal development can produce major changes in behavior well after birth. In view of this information, what has been the effect of that information on your programing?

Dr. **Brandt**. Well, it has had an effect in the following ways. It has largely had an effect on our programs in attempting to improve the educational effort that we make to the professions and to the public generally about nutrition and nutritional practices, both during pregnancy and infants after birth.

The efforts at breast feeding which have now driven those rates up in this country, from roughly 21 percent 10 years ago to 58 percent now, is an indication of part of the success of our efforts at trying to improve the health of infants.

I happen to sit as the U.S. representative on the World Health Organization. We are probably the highest developed country with this rate of breast feeding now in the world and one——

Mrs. **Johnson**. Excuse me, perhaps I misunderstood your statement. You say protein deficiencies during fetal development——

Dr. **Brandt**. Yes.

Mrs. **Johnson** [continuing]. Which I would assume was——

Dr. **Brandt**. I think I just went beyond that. But the efforts during fetal development are aimed principally at providing information to the public and to pregnant women and to the profession about good nutritional practices and trying to give the kinds of guidelines and advice that they can use.

Mrs. **Johnson**. So, that your research on the impact of protein deficiency and also through the evidence that you recently have developed as a result of a long study on the impact of alcohol consumption during pregnancy and the risk this poses to the unborn, it seems to me, should have a dramatic impact on the provision of Federal moneys and the constraints that we impose on States for the use of that money.

I just wonder if that is indeed happening or is your department providing any direction to departments that actually provide programs and send moneys to the States, or do you send moneys to the States to which you could tie some conditions to better deal with the issue of alcohol education during pregnancy and fulfilling protein requirements?

Dr. **Brandt**. Well, we try to advise the States. As you know, the principle underlying the block grant is not to put any more conditions on the States. It's to let the experts make the judgments as to what is needed among their people. And that is what we are attempting to let them do. We do provide them with information; we do provide them with educational material. And under the Alcohol, Drug Abuse, and Mental Health block grant, a fair amount of emphasis is put on fetal alcohol syndrome as well as under the other programs that the States operate.

Mr. **Lehman**. I want to thank the panel for being here today. Those members who wish to submit additional questions for the record will be allowed to do so.

We will now call up the next panel, Dr. Falkner, Dr. McGaugh, Dr. Ouellette, and Dr. Greenspan.

Dr. Falkner, we will ask you to begin and, if possible, summarize your statement and the entire statement will be submitted for the record, and each of the other members of the panel, of course, will also have their opening statements and then we will have questions.

Dr. Falkner, will you begin.

STATEMENT OF DR. FRANK FALKNER, PROFESSOR AND CHAIRMAN, MATERNAL AND CHILD HEALTH PROGRAM, SCHOOL OF PUBLIC HEALTH, UNIVERSITY OF CALIFORNIA, BERKELEY, CALIF., AND PROFESSOR OF PEDIATRICS, SCHOOL OF MEDICINE, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO, CALIF.

Dr. **Falkner**. Mr. Chairman, I would like to, if I may, Mr. Chairman, summarize various key issues in my statement.

Since a healthy and happy outcome for an individual child is surely the goal of those concerned with children, youth and families, certain key issues in the achievement of this goal need presenting.

Whilst birth is a dramatic important event for a mother, it detracts from the human biological fact that it is but one station on the human growth line. The wise ancient Chinese celebrated a child's first birthday at his or her time of birth. This recognized that perhaps the most important year of growth—albeit short 12 weeks of 52—had already occurred, though in utero. Thus growth is a continuum and starts at conception.

As an illustration of the importance of this prenatal growth, which we think is so terribly important, we can use the illustration of an infant of low birthweight. I am sure the committee realizes that the international agreement is to call any baby born alive weighing 2,500 grams or less an infant of low birthweight.

Not all that long ago, we called all such babies premies, or preterm babies, and we now know that is inaccurate, that there are different kinds of infants of low birthweight, not only of a scientific interest but interesting because of the different outcome for these different kinds of infants of low birthweight.

The two kinds are obviously the truly pre-term infants, the one infant born before 40 weeks, and therefore born, obviously, of a light birthweight. But there is another very important kind of infant of low birthweight; they are known as small-for-gestational-age infants, the infant born too small although he or she has been in the uterus for nearly the correct time.

Perhaps the committee would be kind enough to look at one table in my statement, it is table 1, on page 2a. I don't want the

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committee to feel that I would like to snow them with very complicated vital statistics, but this table, if I could go through the key points on it, I think is rather dramatic and certainly shocking to me. The table summarizes the total number of live births in 1 calendar year in the world.

Let me say at once that these are estimates. Estimates from WHO are usually pretty good, but I wouldn't want the committee to think that these figures are absolutely hard data cast in iron.

You will notice, first of all, concerning infants of low birthweight, that in the developed world, there are approximately 1 million born alive in 1 calendar year, whereas in the developing world there is almost a twenty-fold increase, 20-plus million. That, to me, is shocking statistic No. 1. But even more shocking are the estimates on the small-for-gestational-age infants, or SFGAI.

In the developed world, I think nearly all obstetricians would agree in their newborn nursery approximately two-thirds of the infants of low birthweight will be truly pre-term infants. One-third will be those of small-for-gestational-age. This percentage is widely found in the developed world. You see in the developing world, the percentage of SFGAI goes up to nearly 80 percent.

The reason I would like to stress this, is that, as I will show you later, the outcome for the two kinds of infants are different; but more important, probably one of the major causes of SFGAI is malnutrition of either the fetus and/or mother. Then if so, that condition is clearly reversible, and it is reversible in many countries, which would, of course, considerably reduce the numbers of infants of low birthweight being born, and therefore reduce the infant mortality rate.

It doesn't matter very much being born small, provided you get very good care in the modern world and that your outcome is good; but you are, of course, at tremendous risk by being so small. That is why if it is preventable, it is something which really should be done.

Some of you could be raising the question of the genetic factors operating in various countries, in various races, and in order to hold that genetic factor steady, we in the Louisville twin study discovered that among many identical twins, who are identical genetically, some pairs of identical twins are born with grossly different birthweights. One pair in particular we followed. One of the twins weighed half the birthweight of his twin, and was not a so-called premature baby because he had been born in fact at 40 weeks of gestation like his twin.

He behaved, however, like small-for-gestional-age infants were thought to behave when a well-known study by Dr. Mary Cruise was carried out in Buffalo several years ago, showing that if the truly pre-term born infant was given good care, and did not have any congenital malformation, that infant by the age of approximately 3 postnatal years would have caught up to where he or she would have been had they not been born too soon.

I stress good care; I stress the no congenital malformation. But in contrast, Dr. Cruise showed that the small-for-gestational-age, tiny babies exhibited catchup early on just like the preterm baby, but then, as it were, ran out of power and did not catchup. Being small doesn't necessarily matter, but it does matter if your head is small, because the head contains the brain, and I shall dwell on that in a few moments.

To return to that monozygous or identical, twin pair we followed. One of the twins behaved exactly like one of Dr. Cruise's small-for-gestational-age infants and did not catch up, nor has he ever caught up; and at the age of 16 he is 7 centimeters shorter than his twin brother. It doesn't matter because they are healthy, did well at school, and their head circumference was, in fact, the same all the way through their growing life.

We have a collaborative study in the city of Montevideo at the Pan-American Health Organization Center for Perinatal Studies. I won't bother the committee with great detail of what the study is doing, except that recently they announced their small-for-gestational-age infants all did catch up and they were very proud of the fact that the Montevideo babies were doing better than the Buffalo ones.

Could I ask the committee if they would look at the later crude illustration, for which I apologize, but which was done by hand in rather a hurry. On figure 1 on page 4a, I would like to explain what the boxes are. The boxes are simply a distribution curve for a particular measure, in this case weight, of all the full-term babies, the healthy, full-term babies in the Montevideo study.

Clearly, then, if you are inside the box, you are behaving for that measurement like a healthy, normal, full-term infant. Each dot represents an individual small-for-gestational-age infant. You will notice, of course, as you would expect, that they are all outside the box at birth. Clearly, by the age of 2 years, for weight, they have all got into the box. This is why the Montevideo colleagues said that all their small-for-gestational-age infants caught up.

If you look, please, at the next figure on page 4b, showing head circumference—a representative measurement of brain size. You will notice that some of the small-for-gestational-age infants are indeed already in the box at birth and that most of them have gotten in by the age of 2 years, but that there remain four outside.

Again, to be repetitive, weight and length and height don't matter very much if you are deficient, provided you are healthy, but head size probably does represent brain development.

Dr. Brandt, in Germany, recently and totally independently, studied in great detail the neurological development of her small-for-gestational-age infants and found, as we have now found, that there are in fact two kinds. There are those who do catch up and do well, and those who do not. Again, if it is brain development that doesn't do well, we think this can be a very serious factor.

I have concentrated rather much on small-for-gestational-age infants. I wouldn't like the committee to think I feel the pre-term, tiny baby is unimportant. Of course they are. If they are too small, they are at risk; they are also immature and therefore don't have the appropriate immunological defenses.

By reducing the incidence of prematurity and indeed reducing incidence of small-for-gestational-age infants, we, of course, will reduce the infant mortality rate by lessening the number of infants of low birthweight which are at such great risk. I would like to summarize, Mr. Chairman, if I may, by quoting from a forward to a recent World Health publication called Prevention in Childhood of

Problems in Adult Life. The foreword is written by Dr. Angèle Petros Barvazian, Director of the World Health Organization's family health division. In her forward she says:

> The remarkable progress achieved in recent decades in means for the prevention and treatment of childhood diseases has unfortunately benefited only a relatively small proportion of the world's children. There has certainly been an overall reduction in infant and child mortality, but in most parts of the world—in the developing countries, particularly—the rates remain disturbingly high, with striking disparities both between countries and between areas or populations within countries. Of some 122 million children born annually, 12 million die before they reach their first birthday. Yet this figure, disquieting though it is, tells nothing of the sad reality awaiting the many millions who survive to become the victims of ill health brought about by a host of adverse socioeconomic factors, most commonly associated with malnutrition, infection and closely spaced pregnancies, or who fail to develop to their full potential.
>
> * * * Another activity * * * was WHO's promulgation in all countries of the theme: "A Healthy Child, a Sure Future." That theme is subsumed in every page of the present book, which addresses itself to many important aspects of the very wide issue denoted by its title.
>
> Much of what is said reflects the increasingly general acceptance in recent decades of the view that preconceptional factors and conditions during fetal life and early infancy profoundly influence the physical and psycho-social development of the child and ultimately the health of the adult. Among the most important early influences is the environment of the family, the basic social unit.

I would like to close, Mr. Chairman, by suggesting that if an infant escapes being an infant mortality statistic and survives, I am pleased that that infant survives. But I am not pleased when an infant survives who is damaged, and is not intact, because he or she will develop into an unhealthy adult. That is why I would like us to concentrate very much on the prenatal period of growth in utero.

[Prepared statement of Dr. Frank Falkner follows:]

Prepared Statement of Frank Falkner, M.D., F.R.C.P.

FETUS INTO MAN: KEY ISSUES IN OUTCOME AND PREVENTION

Since a healthy and happy outcome for an individual child is surely the goal of those concerned with children, youth and families, certain key issues in the achievement of this goal need presenting.

Whilst birth is a dramatic important event for a mother it detracts from the human biological fact that it is but one station on the human growth line. The wise ancient Chinese celebrated a child's first birthday on his or her time of birth. This recognized that perhaps the most important year of growth—albeit short 12 weeks of 52—had already occurred, though in utero. Thus growth is a continuum and starts at conception.

As an illustration of the importance of this pre-natal period of growth we can turn to the area of infants of low birth weight, and glean, with benefit, some helpful information from data gathered in the developing world.

Not all that long ago, infants who weighed 2500 gms. or under at birth, were called "premies" or prematurely born infants (PTI). Of recent years, we have found that such infants of low birth weight (ILB) are by no means all born too soon. Small-for-gestational-age-infants (SFGAI) are those born too small: that is they have remained in utero for near, or the correct, time yet are still born an ILB.

It could be said that the above is of scientific interest only in that ILB, because of their smallness, are at great risk in the neonatal period, whatever the cause of their smallness. This over simplification is indeed true, and reducing the number of ILB born will lower an infant mortality rate—whatever the cause. Added to this, however, is the difference in outcome for different groups of ILB.

The vital statistics shown in Table 1 are rather shocking and give estimates (from my colleagues at WHO) of the total world live births estimated in 1975, of which 22,000,000 were ILB; 21,000,000 of those infants were born in the developing world; over a million were born in the developed world. So, there is a 20-fold increase in the number of ILB born in the developing world. That is the first startling statistic.

The second is more shocking, but interesting scientifically. The proportion of ILB, who are PTI in the developed world, is roughly two-thirds. Thus, about one-third are SFGAI. Exactly the reverse occurs in the developing world, where almost 80% of those falling into the ILB category are SFGAI. The reason this is so shocking is that presumably one of the factors involved in the causation of SFGAI is almost certainly malnutrition—either fetal or maternal. Therefore, many of those infants who are born SFGAI and hence at risk, are the result of a condition that can be reversed.

More applicable to the developed world, it is apparent that heavy smoking mothers during pregnancy, and those who do not gain appropriate weight, are examples of reversible causation of SFGAI.

ANNUAL WORLD LIVE BIRTHS ESTIMATES*

A.	TOTAL WORLD LIVE BIRTHS	137,000,000
B.	TOTAL WORLD ILB (RANGE 4-45%, ACCORDING TO POPULATION)	22,000,000 (16%)
C.	TOTAL DEVELOPING WORLD BIRTHS (85% OF A.)	116,500,000
D.	TOTAL DEVELOPED WORLD BIRTHS (15% OF A.)	20,500,000
E.	TOTAL ILB IN DEVELOPING WORLD (18% OF C.)	20,900,000
F.	TOTAL ILB IN DEVELOPED WORLD (5.5% OF D.)	1,100,000
G.	PERCENTAGE OF ILB IN DEVELOPING WORLD THAT ARE SGAI = 75% OR ...	15,600,000
H.	PERCENTAGE OF ILB IN DEVELOPING WORLD THAT ARE PTI = 25% OR ...	5,200,000
I.	PERCENTAGE OF ILB IN DEVELOPED WORLD THAT ARE SGAI = 33% OR ...	365,000
J.	PERCENTAGE OF ILB IN DEVELOPED WORLD THAT ARE PTI = 66% OR ...	725,000

Note: Infant Mortality, 1972: World = 98 (range 16-178); U.S.A. = 18.

*Source: WHO, January 1979

Abbreviations: ILB=Infants of Low Birth Weight

PTI=Preterm Infants

SFGAI=Small for Gestational Age Infants.

TABLE 1.

As regards all important outcome: First a word on growth velocity. We are used to thinking in terms of human size achieved at various ages. A more important concept is that of growth velocity—rate or speed of growth at various ages. Two examples at opposite ends of the spectrum are a) zero growth velocity. Growth has ceased and if this occurs during the normal growth period, it clearly signals a serious impairment in need of investigation. By contrast, b) so called "catch-up growth" is a phenomenon whereby an individual grows notably faster than "normally" in an effort, as it were, to make up for a previous deficit.

Cruise (1973) in Buffalo, did a good longitudinal study for the first three years of life of ILB and full-term infants (FTI) in her clinic. She demonstrated that PTI who were not suffering from any congenital malformation and were given first-class care had, on average, exhibited catch-up growth and achieved the same mean size as a FTI by 3 years of age.

By contrast, the SFGAI exhibited marked catch-up in the first 18 months of life (as did the PTI) and then the catch-up process and fast growth rate ended. Therefore, by the time SFGAI were 3 years postnatal age, they had not caught up to the FTI. those, though over-simplified, were Cruise's findings.

A study of identical (monozygous) twins (Falkner 1978) showed that even when holding the genetic factor and influences the same (as of course they are in identical twins), one twin was born a SFGAI at 39 weeks gestation weighing half the birth weight of his FTI twin. The small twin behaved exactly as Cruise's average SFGAI and although healthy at 16 years of age is considerably smaller in body size than his FTI twin. Surely not of importance if both are healthy? Both performed similarly and well in school performance and their head circumference growth was similar and did not exhibit notable size differences. This leads to further potentially important considerations.

A review of some data from the Centro Latinoamericano de Perinatologia, Montevideo, led us to the realization that, in fact, there is almost certainly a distribution curve of SFGAI with both ends demonstrating either good catch-up and outcome or no catch-up and poor outcome. Could it be that Cruise's sample was biased in that her SFGAI sample contained a preponderance of poor-outcome infants?

Figure I shows the growth pattern of individual SFGAI (represented by separate dots) for body weight. The boxes represent the distribution curve for weight got FTI in the Montevideo sample. All the SFGAI have indeed entered the box by two years of age exhibiting the reverse of Cruise's findings in Buffalo.

Figure II shows, by contrast, that some SFGAI for head circumference are already in the box at birth, and four individuals did not exhibit sufficient catch-up to enter the box by two years of age. This can profoundly influence outcome, for head circumference is a good indicator of brain growth—particularly over this critical period of brain development. Such critical periods will be addressed by the expertise of a colleague later in this record.

Thus we found the Montevideo comparatively small sample was biased in the opposite direction to the Buffalo infants in that the pre-ponderance in Montenvideo was of SFGAI destined to do well, hence causing the better outcome average. Figure 3 shows the poor outcome for head circumference of tow individual SFGAI, numbered 8 & 7.

FIGURE 1

Body weight:SFGAI/FTI distribution curve.

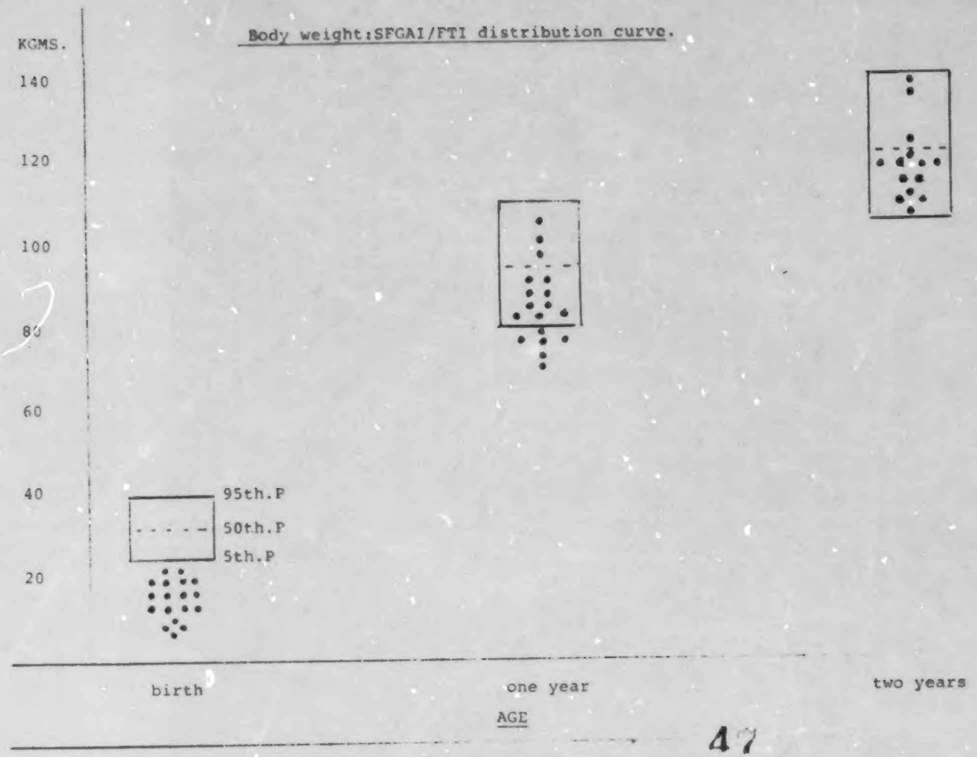

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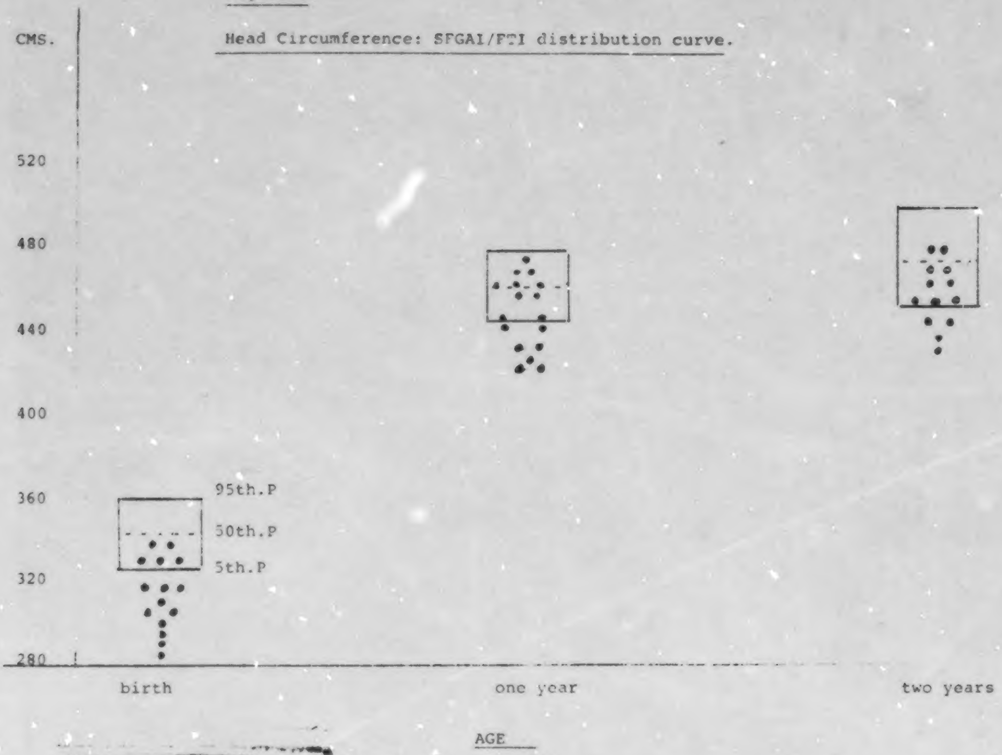
Figure 2.

Head Circumference: SFGAI/FTI distribution curve.



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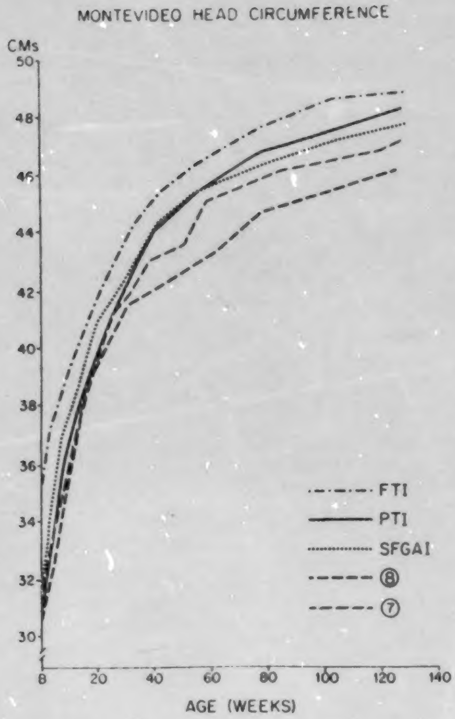
Now we feel there is a distribution curve for SFGAI as regards good or poor outcome. Brandt (1978) in Germany, in some sophisticated longitudinal studies of neurological development discovered, independently, that among her small group of SFGAI in the first 2 years of life, there were those who exhibited a deficiency in neurological development compared to another group that did not. This again emphasizes that whilst size may not be all that important, neurological-mental development is clearly so.

An immediate goal to be pursued is monitoring of fetal prenatal growth so that predictions can be made on fetal outcome and the relationship of such to environmental and genetic factors acting upon the mother, examples being nutritional, infectious disease, poor social conditions, and drug abuse. With the advent of non-invasive ultra-sonography and sequential post-natal follow-up, the goal can be achieved and causative factors that are reversible eliminated.

The center of this discussion having been to this stage the SFGAI, this should not lead to the assumption that the ILB who is a PTI is not so important. The PTI, in addition to being tiny, is also immature and a notable proportion of whom will be born with a congenital defect(s). Thus intensive investigation is needed into the causation of prematurity, the successful treatment of such would markedly reduce an infant mortality and infant and childhood morbidity rate.



Abbreviations: FTI=Full Term Infant
PTI=Preterm Infant
SFGAI=Small for Gestational Age Infants

Figure 3.

As an overview, then, of human growth, not forgetting the prenatal precursors, a healthy infant seems destined to seek an individual velocity curve. Once growth is progressing along this curve, it is not likely to be deflected permanently unless the environment becomes and remains inadequate. Various impairments to growth may cause the velocity to fall below the level of the curve, but with the impairment removed and suitable intervention, catch-up growth can occur during which the velocity will rise above the level of the curve to compensate for the earlier slowing down or cessation. If the impairment is severe enough, or operates over a lengthy period, catch-up growth will not occur. This is of crucial importance when certain organs and systems are going through critical periods of development. For example, for the brain, this is from about the thirty-second week of fetal life to about the second postnatal year. Lack of appropriate environmental factors, or impairments, during this period may then cause reduced or defective growth of the brain, with no catch-up and hence an irreversible arrest, ultimately resulting in a greater or lesser deficiency in the mental performance of the adult.

We often in good faith and the best of intentions launch intervention projects for the hoped for benefit of deprived and non-intact infants. Such intervention post-natally is all too often sadly too late.

SUMMARY AND CONCLUSIONS

Perhaps the most contributory way of closing this statement is to quote from a recent trenchant Foreword to a W.H.O. publication Prevention in Childhood of Adult Problems in Adult Life (Falkner 1980), by Dr. Angele Petros Barvazian, Director of W.H.O.'s Family Health Division.

"The remarkable progress achieved in recent decades in means for the prevention and treatment of childhood diseases has unfortunately benefited only a relatively small proportion of the world's children. There has certainly been an overall reduction in infant and child mortality, but in most parts of the world—in the developing countries, particularly—the rates remain disturbingly high, with striking disparities both between countries and between areas or populations within countries. Of some 122 million children born annually, 12 million die before they reach their first birthday. Yet this figure, disquieting though it is, tells nothing of the sad reality awaiting the many millions who survive to become the victims of ill health brought about by a host of adverse socio-economic factors, most commonly associated with malnutrition, infection and closely spaced pregnancies, or who fail to develop to their full potential.

Another activity . . . was WHO's promulgation in all countries of the theme: "A Healthy Child, A Sure Future." That theme is subsumed in every page of the present book, which addresses itself to many important aspects of the very wide issue denoted by its title.

Much of what is said reflects the increasingly general acceptance in recent decades of the view that preconceptional factors and conditions during fetal life and early infancy profoundly influence the physical and psycho-social development of the child and ultimately the health of the adult. Among the most important early influences is the environment of the family, the basic social unit."

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Mr. Lehman. Thank you.

We have got to recess for 10 minutes to go over to the House floor to make a vote and we will be right back.

[Recess.]

[Information requested by Hon. Thomas J. Bliley, Jr., follows:]

Congressman Thomas J. Bliley, Jr. has submitted the following question to Frank Falkner, M.D., for the record:

You have pointed out that 66 percent of low birth weight babies in the developed world are truly premature and only the remaining ⅓ and small for gestational age.

This fact suggests to me that by focusing our prenatal programs primarily on nutritional needs we are targeting our resources toward one-third of the "at risk" population, but giving the two-thirds of that population less attention.

I understand that the causes of premature birth are not linked primarily to nutrition, but to other facts both medical and non-medical. Could you address this subject?

UNIVERSITY OF CALIFORNIA, BERKELEY,
Berkeley, Calif., August 23, 1983.

Hon. THOMAS J. BLILEY, Jr.,
Member, Select Committee on Children, Youth, and Families,
U.S. House of Representatives, Washington, D.C.

DEAR REPRESENTATIVE BLILEY: I am grateful for your interest, conveyed to me by Congressman Miller, and am very happy to address the important question you raise.

I had pointed to the much, much higher percentage of small-for-gestational-age infants (SFGAI) in all infants of low birth weight (ILB) in the developing world, when compared with the one-third in the developed world. I did so to illustrate that since maternal-fetal undernutrition is likely a major factor in the causation of SFGAI, that condition is reversible. Thus in pockets of the U.S.A. population, where such conditions and percentages may be similar, SFGAI may be largely preventable.

ILB are all at risk whatever the cause; and since 66 percent are truly prematurely born in our developed world, the causation of prematurity must be most vigorously sought. I perhaps did not stress this enough in my presentation, which was an unintended omission. This may be due to the fact that we have many clues about causation of SFGAI (example: undernutrition), but virtually zero on the etiology of prematurity. The attention, then, on the 66 percent of that population is to first find out how prematurity can be prevented.

I hope this answer is helpful and demonstrates, too, my unintentional errors and slant.

Yours very sincerely,

FRANK FALKNER.

Mr. LEHMAN. The committee will now come to order, and the next gentleman on the panel will be Dr. McGaugh.

STATEMENT OF DR. JAMES L. McGAUGH, PROFESSOR OF PSYCHOBIOLOGY, AND DIRECTOR, CENTER FOR THE NEUROBIOLOGY OF LEARNING AND MEMORY, UNIVERSITY OF CALIFORNIA, IRVINE, CALIF.

Dr. McGAUGH. Mr. Chairman, members of the committee: I am pleased to be here to have this opportunity to tell you a little bit about recent neuroscience research concerned with the development of the brain and, in particular, with a focus on the implication of these findings for the development of cognitive process; that is, the processes that allow us to learn and remember and think, and so forth.

Now, there has been much of discussion today about the development of the child and the development of the brain—and we have even had it pointed out that the brain is located in the head, which saves me a little time in my presentation——

Chairman MILLER. Maybe we should go over that again.

Dr. McGAUGH. The purpose of having a brain is to provide for plasticity; for us to benefit from the experiences that we have to learn and to remember.

This is an absolutely key aspect, because it is through learning that we become what we are. Everything that we are as human beings depends upon things that we have learned and remembered. That is what we are. All of our memories, in the first instance, all of our hopes. our plans, our dreams, our talents, and so on are all fundamentally based on things that we have acquired with experience that we have had. That is why it is so fundamental to understand the brain, because the brain is the organ of the body which allows all of these things to happen.

Now, the second point is, as we already know, that the brain is not given to us all at one time but the brain develops and develops over a long period of time. There are a number of stages in the development of the brain, and a key point that I want to emphasize is that each of the stages in brain development builds upon what has been developed before, so you have an accumulation of factors. If there is a bad brain early in development, there will be a bad brain later in development, and always in development, because each of the stages builds on the early stage.

Another point that I want to make is that the brain is a highly plastic organ, that it has the capacity for change, and it retains that capacity through life. That is even in the oldest of ages of human beings there is still brain plasticity. I can return to this. But it is also the case that brain plasticity is the greatest early in life. So the opportunity to influence the brain, influence its direction and then its ultimate development, is greatest early in life, starting prenatally and then in early childhood.

Now, there are a number of, let's say, normal influences as opposed to toxic influences, and so forth, that are involved in brain development. The first of these is under genetic control, the development fundamentally of the cells of the brain. The cells of the brain develop in most regions of the brain by the time of, let's say, 1 month before birth. So when we have birth minus 1 month, we have most of the cells that we now have in our brain, although some of us had begun to lose some—particularly after the age of 25, we begin to lose cells.

Now, the brain, however, is not complete at that time. The brain continues to grow and develop and reaches an adult size at about the age of 7. It is about 2½ times the size at the age of 7 that it was at the time of birth. No more cells—that is not correct; not very many more cells are developed. There are a few regions of the brain that continue to develop after birth, but that is a small number of regions. But not many more cells are developed after birth.

What happens is two things. One is there is a growth of the pathways connecting the various regions of the brain; that is, getting the cells to communicate with each other. And then, beyond that, to develop the synaptic connections; that is, the connections among the nerve cells, the places that nerve cells actually talk to each other. Now, it is this latter process, the development of the connections between the nerve cells, that continues throughout life, continues to develop forever, at this very moment, and in the very brains right now synapsis are being developed.

Now, interventions at any time in the development will produce consequences. We have heard about the Fetal Alcohol Syndrome and a number of conditions that affect prenatal development of infants. I would like to focus for a moment on something that may be less obvious but perhaps equally or maybe even more important. That is the role of environmental experience on brain development.

It is not the case that these processes of brain development are entirely endogenous. It is not to say that the development of the brain is like a Japanese flower which just unfolds in a preformed fashion. There is some unfolding over a preformed fashion in the making of the cells that are going to be the constituents of the brain, but the nature of the pathways and the nature of the connections depend upon the environmental influences, hormonal influences and other influences the brain is subject to.

I would like to give you a couple of examples perhaps that will illustrate this. One example is the development of the visual system, because this has been so eloquently worked out. In studies with laboratory animals, it has been shown that if animals are deprived of certain kinds of complex patterns of visual stimulation while they are developing in the early stages of their development, they will never be able to see those patterns later in life. That is, the absence of that stimulation at a critical period of the brain's development results in a brain which is forevermore absent in the ability to perceive that complex stimulation which wasn't there. So here is a long-lasting permanent effect on brain development that comes simply from environmental stimulation.

Second, there are now extensive studies showing that the detailed structure of the brain in laboratory animals depends upon the kind of environmental stimulation that animals have, particularly when they are young. In these experiments, animals—they are usually rats, but they can be all kinds of animals; it has been done with squirrels, with cats, with most of the laboratory animals you can think of—are reared in different types of environments. Some are put into normal laboratory cages; some are put into laboratory cages that are devoid of any sensory input—they are like prison cells; and a third group ordinarily is put into a laboratory environment that has slides and swings and colored objects and balls to play with, and tinker toys and all the things you can imagine—the best environment that the University of California can provide for developing laboratory animals. These experiments were done, by the way, by my colleagues at Berkeley not too many years ago.

Now, what happens is that after the animals are reared and their brains are analyzed, it turns out that the brains are really very different. The brains of the animals reared in the complex environments are larger, they are heavier, they brain cortex—which is the outer bark of the brain and the region of the brain most highly developed in human beings—is thicker, and, most importantly, there is an increase, dramatic increase in the number of synaptic contacts; that is, in these animals that have been exposed to enriched environments, the number of cellular connections is greater.

I think that is the bottom line on this. They have a brain that has been wired in a more complex fashion as a function of just a modest amount of environmental stimulation in comparison with the normal animals and, even worse, the comparison with the animals that have been deprived, whose brains, by inference, are smaller and less complex, and dramatically so.

Now, I want to emphasize that the plasticity of the brain, as I have said earlier, the ability to make these connections, does not disappear as the animals develop. Indeed, very old animals can make new synapses. That is, the connection between nerve cells, they make them much more inefficiently, infrequently, and their pattern of wiring is much less complex. Now, these effects can have some really long-lasting effects on development that are seen later in life.

Let's go back to something that was mentioned this morning, phenylketonuria, which is a genetically based disease which has the consequence of having children who are unable to metabolize the amino acid. Phenylalanine in high concentration is toxic to the brain. If nothing is done for these children, then their brains do develop abnormally, they will be mentally deficient.

A number of years ago it was shown that it is possible to rear these children on diets low in phenylalanine and the children can develop rather normally; that is, the disease can be attenuated quite a bit through dietary control. The point I want to make here is in the case of phenylketonuria, the mental disability is seen early on and it is lasting, if nothing is done.

There are other effects on the development which I would like to refer to as time bombs, in the sense that they are set by conditions that occur early in life, but one doesn't see the consequences until much later in life. So they are not so obvious. They are the ones I think we should be concerned about. They may turn out to be more difficult to understand, but in the long run they may have greater effects.

Let me divert for a moment and give you some examples from some laboratory animals which will illustrate the point. Then I will return to the human example. I would like to give an example from the development of birdsongs in the White Crown Sparrows, which grows in northern California, in the bay area, and perhaps Congressman Miller has seen White Crown Sparrows in his neighborhood there.

Now, the White Crown Sparrow is interesting because the song that it sings as an adult is a song that it has learned when it was an infant. It learns this when it is very young, when it is a juvenile, and does not sing it—only listens to it. Later on in life, when the bird is matured and the hormones appear, then the hormones elicit the birdsong which was learned early in development. If that bird is not allowed to listen to a correct song, or if it is taught, it listens to that, an incorrect song, it will never be able to sing the correct song in adulthood. That is, the brain gets wired in a different way and there is no therapy for it. It is all over.

You may say, so what; this is a bird. It may also interest you to know that the birdsong is lateralized in the bird; that is to say, it is located in the left hemisphere just as language is in the left hemisphere of humans. One, I think, has to be caused to wonder whether there are some analogues between the learning of this kind of language in the bird and the learning of this kind of language in the human. It is probably not an accident that children learn most of their language by the time they are 5 years old. Remember, the brain is completely developed by the age of 7.

I would submit that in all likelihood there are critical periods for the development of language which have not been addressed systematically. Now let me give you a couple of examples more neurobiological which I think are interesting and have great implication.

There are a number of structures within the brain that are known to be importantly involved in learning a memory. One of these regions is in a lumphic system and it is called the hippocampus. You do not have to remember that. I should tell you what the structure is.

In laboratory animals, in some cases if lesions are made—chemical lesions are made by removing heavy metals from certain cells in the brain, these brain cells require zinc for correct functioning—if the zinc is removed during the early stages, no effect is seen on the behavior until much later in life. When the animals are mature, then they have defects in their ability to learn and remember. The reason that the defect was not noted earlier in life is simply because these structures are not required for learning early in life. They don't develop until later. This is one of the regions of the brain that develops after birth of the animal rather than before.

So here is a delayed time bomb effect. Something is done to the nervous system early on; no defect is determined. Later on when that system of the brain is required for functioning, the animal has a deficit in its ability to learn and remember. Now I point this out because of some very recent studies that have been done both at the National Institutes of Mental Health and out in California showing that in the human brain there are different neuronal structures that underlie different kinds of learning, and I will not go into detail here but I can do it simply by saying that it is pretty clear now that the systems in the brain that underlie our learning of factual details, that this happened at this time, that this is going on at the present time—for example, your memory of the brain structure hippocampus and so on—that memory system is a different one from the memory system that enables you to learn to write, to drive a car, to play tennis and so on.

The learning of skills is very different from the learning of factual information. And it turns out that the hippocampus is a very important structure involved in the neuronal system underlying the learning that things happen, of events, of times, and so on. And one would want to pay great attention to the possibility that early conditions may have effects on the hippocampus, in the development of the hippocampus, which will show up later in life as disorders in learning and memory in children.

Let me turn to a couple of disorders in children about which we don't know very much and about which we should know a lot. First, autism—I will mention it briefly. You are no doubt familiar with a very debilitating childhood disorder, autism, in which we are simply unable to teach the children very much, and they are a heavy load on parents and on our society. One, I think, has to ask the question: What are the early influences on the development of children which lead to the autistic response? And we simply cannot know.

Another example is the attentional disorders in children's systems called hyperkinesis. You may have heard about this and you may know it is a disorder which is seen very extensively. It is a major problem for parents and it is a horrendous problem for schools, because these children in many cases are hyperactive; in all cases, have attentional disorders. They cannot attend to things for a very long period of time.

It is assumed that the disorder is caused by early small brain damage. As a matter of fact, when it was first noticed it was called minimal brain damage disorder. We don't know what causes the disorders, these attentional disorders. We need to know a lot about them. Presumably, early conditions, early treatments, early influences are responsible for this disorder.

Now, in this case, unlike autism, something can be done. There exists a number of drugs that can be given to children with disorders of attention, and they are moderately effective. All of these drugs are central nervous system stimuli. These children who have them can be brought under some kind of control ordinarily through the use of drugs. In the case of autism, there is no therapy I, as yet, know for that.

Now, are there learning and memory disorders in adults that are related to early development? We simply don't know. Are there delayed symptoms like the ones I described for the animals? We don't as yet know very much about the causes of Alzheimer's disease. It is possible that Alzheimer's disease results from some early interference with the developmental phase in the brain and then is only seen later as a bomb that is going off having been set early in development. We simply don't know. We need more research to find that out.

Can something be done? Well, like the treatment of children with attentional disorders, I think that within a fairly short period of time—meaning a decade or two—there might be some therapy for the treatment of disorders of learning and memory in adults. Much current research focuses on hormones and their influence on learning and memory. My own laboratory investigated the effects of hormones on learning and memory in adults and animals, and also in very old animals. We are working with a strain of rats, for example, that learns quite well when they are aged but forgets very quickly, as many aged adults do.

We find that we can alleviate this disorder or we can, if you like, eliminate the memory problem in old laboratory animals by treating them with the right kinds of hormones at the right time. This kind of research suggests a possibility that even if there are such time bombs, it might be possible to alleviate the difficulties, at least to some extent, later on.

Now, let me summarize by giving you what I think are some of the implications of the kind of work that I briefly summarized here. First of all, I think that there is abundant evidence of critical periods in early development of the brain and in the development of behavior, particularly cognitive behavior, that results from the development of the brain. I believe that we need to do what we can to prevent the disorders which are now understood and, for example, in the case of phenylketonuria, much has been done.

There is automatic screening. A routine screening is done of infants for phenylketonuria. I don't know how much is being done to insure that early in childhood that children are exposed to the right kind of environmental stimulation. I don't know if, say, the latch key child is being subjected to the same kind of environment that laboratory animals reared in deprived environments are being subjected to. I think it is a very interesting question, because, if they are, you can certainly expect there will be long-term cognitive disabilities that will result from that deprivation. So the recommendation here is to consider more prevention for those disorders which are now understood.

Second, we need more research concerning those disorders that are not understood, research of two kinds. One concerns the mechanisms. In autism, for example, there seems to be good reason to believe that that is a developmental disorder. It is a very debilitating disorder, and basic research is needed on the underlying developmental cause. Second, more research is needed with regard to the potential therapy or treatment of disorders after they occur.

My final point is that these days, quite properly, we are hearing an awful lot about the importance of education, and the media is full of questions about what is going to be done for the sorry plight of national education. Let me remind us all that when we talk about education, we are talking about the brain, because the brain is the organ of education; and education absent a good brain will not be very effective.

I think that it is in our best interest to get the most out of our best national resource, which is a healthy brain that is developed adequately.

Thank you.

[Prepared statement of Dr. James McGaugh follows:]

PREPARED STATEMENT OF JAMES L. MCGAUGH, DEPARTMENT OF PSYCHOBIOLOGY AND CENTER FOR THE NEUROBIOLOGY OF LEARNING AND MEMORY, UNIVERSITY OF CALIFORNIA, IRVINE

Mr. Chairman, Members of the committee, I am pleased to be here. I thank you for the opportunity to discuss with you some findings of neuroscience research which have important implications for child development. My remarks are focused on research concerned with the development of cognitive processes.

Let me begin by emphasizing that our abilities to learn and remember are our most fundamental human capacities. One of the most obvious facts of experience is that we are changed by our experiences. We learn to walk, to speak, to read, to understand and to think. Our skills, our hopes, our plans, and our decisions are all based on our ability to learn and remember. It is also important for me to emphasize that all influences on our cognitive abilities directly affect how we behave and what we may achieve as individual human beings.

The brain is our most important organ. The brain processes information provided by sensory stimulation, that is, from the eyes, the ears, the skin, and so forth, and the brain coordinates and directs our responses. The nature of the information processing and the coordination of responses depends, to very considerable extent upon influences that shape the brain's development. I would like briefly to summerize some of the main features of brain development and to inducate their significance for the development of cognitive processes.

It is essential to recognize that the development of the brain involves many brain systems and that there are a number of developmental stages. The early stages of development are of critical importance since the processes developed in early stages influence all subsequent development. Each stage of development is built on the results of earlier stages. It is also important to recognize that the brain is a highly plastic organ. The organization and the functioning of the brain continues to change throughout the lifespan. But, different processes underlie plasticity at different stages of life and the degree of plasticity generally dereases with age.

The initial development of the brain is rapid. The cells in most regions of our brains were developed a month or so before we were born. By the age of 7 our brains were about the size that they are now—more than double the size of an infant's brain. For the most part, postnatal development involves the development of the pathways connecting different brain systems as well as the specialized systems for communicating between cells, referred to as synapses. Conditions which influence the development of brain cells will, of course, fundamentally affect the subsequent development of neural pathways and connections between cells. Early brain development is regulated by genetic systems and is markedly affected by hormones and other biochemical influences including diet and drugs. Studies of laboratory animals indicate that the brains of males and females are anatomically different and that the differences are due to hormonal influences early in life. As the brain develops it is highly sensitive to influences resulting from environmental stimulation. In fact, the development of brain systems depends critically on sensory stimulation. Studies of the development of the visual system indicate that the patterns of stimulation that the brain sees early in development determines what patterns the brain will be able to see later in development. Restrictions of patterned visual stimulation produce lasting deficits in perception. It seems highly likely that these principles based on visual perception will hold for the development of other abilities. Available evidence indicates that it would be unwise to assume otherwise. I will return to this issue later in my remarks.

Many details of brain structure are shaped by the sensory environment. The size of certain brain regions—including the thickness of the cerebral cortex (which is the most highly developed structure in the human brain)—is influence by the complexity of environmental stimulation. The brains of laboratory animals reared in complex environments are larger than those of animals reared in unstimulating environments. Further, different environments produce brains that differ in anatomical detail. Animals from enriched environments have more complex nerve cells in the cerebral cortex and have more synaptic connections on each cell. To put it another way, environmental stimulation appears to shape the wiring of the brain. Further, the effects of early environmental stimulation are lasting. I would like to emphasize this major point. Our experiences have shaped the detailed anatomy of our brains. The greatest shaping occurred early in our lives. But it is continuing to a lesser extent even today and at this moment.

Because of the importance of early development, conditions affecting the brain development have long-term consequences. Children with the condition called phenylketonuria are unable to metabolize the amino acid phenylalanine. An excess of this amino acid has damaging effects on the brain. If such children are given diets low in phenylalanine early in life, the damage is lessened and the behavioral consequences are less severe. In the case of phenylketonuria the condition can be readily diagnosed and, if left untreated, the consequences are readily observed. Other conditions affecting early development may not be so readily apparent. Conditions affecting brain development may, under some conditions, be like "time bombs" in that the consequences may be revealed only much later in life. Studies of song learning in birds indicate that young birds of some species learn the song of their particular species simply by listening to adult birds sing. As they develop and reach sexual maturity, the singing of the song learned early in life is stimulated by sexual hormones. If the birds are not exposed to songs during the early critical period or if they are exposed only to songs of other species they will, at maturity, not be able to sing the correct song. That is, a behavioral disorder that developed at an early critical period in brain development is not revealed until a much later time. Children learn the language of their culture—and learn it quite well—largely within the first five years of life. The early years may well be a critical time for the development of language skills. Other studies using laboratory animals have shown that strains of animals that have different patterns of organization in a particular brain region differ in ability to learn certain problems. The differences in learning ability are seen only after the development of the particular neural system—which is not present at birth. Other studies have shown that if this brain region is damaged during development the animals will have a learning deficit that is seen when they are mature—that is, after the normal period for the development of this brain region.

As yet little is known about the causes of disorders of learning in children. It may well be that autism and attentional disorders (sometimes term hyperkinesis) are caused by conditions affecting early stages of brain development. It might even be that late developing congitive disorders such as Alzheimer's disease are "time bombs" set by injury or disease during critical periods of early development.

The abundant evidence for critical periods in the development of the brain and behavior in laboratory animals clearly suggests that there are critical periods in our own early development. All of this evidence clearly argues for the importance of understanding human brain development and for taking steps to insure that developmental disorders are prevented. While much has been learned in recent years we still know much too little. Until we know more about the causes of specific disorders we will not have specific means of preventing them. It should be noted that some treatments are available for certain disorders which are not yet understood. For example, in some children attentional disorders that lead to learning difficulties are effectively treated with drugs. Studies in laboratory animals have shown that learning and retention can be enhanced by drugs and hormones. Further, the decline in learning and memory seen in old animals can be reduced by hormone treatments. These findings strongly suggest that further studies will lead to effective treatments for cognitive disorders which occur later in life. Prevention of disorders is, of course, not cost free. But evidence from recent neuroscience research gives good reason to believe that research leading to an increased understanding of brain development and changes throughout the lifespan will be cost-effective. We can pay now by supporting the costs of research and by providing appropriate conditions for developing brains or we will certainly continue to pay later.

Thank you.

STATEMENT OF DR. EILEEN OUELLETTE, DIRECTOR, UAF, SHRIVER CENTER OF MENTAL RETARDATION, ASSISTANT PROFESSOR OF NEUROLOGY, HARVARD UNIVERSITY MEDICAL SCHOOL, AND ASSISTANT PEDIATRIC NEUROLOGIST, MASSACHUSETTS GENERAL HOSPITAL

Dr. OUELLETTE. Mr. Chairman, members of the committee: I have been asked to talk about the fetal alcohol syndrome this morning. I arrived late from Boston. I understand that someone else already talked somewhat on the fetal alcohol syndrome, so I will try to shorten this so I won't be too redundant.

Fetal alcohol syndrome, FAS, refers to a series of effects seen in children of women who chronically drink alcohol to excess during, and possibly prior to, pregnancy. Now there is a list of minimum criteria which have been accepted for one to be able to diagnose fetal alcohol syndrome. There are three major categories of abnormalities seen in these children that, one, they show prenatal and/or postnatal growth retardation, with weight, length, and/or head circumference below the 10th percentile. So the important point here is that these children's brains are smaller than normal.

Second, they show central nervous system involvement. They often show neurologic abnormalities, developmental delay or intellectual impairment and mental retardation.

Third, they show a variety of birth defects, dysmorphology, and they should show at least two out of three of the following signs for us to make this diagnosis. One is the small brain, microcephaly; the second is microphthalmia, small eyes, and/or short palpebral fissures. This is, the horizontal length of these children's eyes are smaller.

The third is poorly developed philtrum—the distance from the base of the nose to the upper lip—thin upper lip, and/or flattening of the maxillary area. Their cheeks are also poorly formed.

This whole spectrum is known as the fetal alcohol syndrome. Fetal alcohol effects, FAE, refers to any abnormalities seen in children as a result of alcohol use by women during pregnancy. It does not require the full spectrum of the syndrome, and it does not require that the mother is herself an alcohol abuser.

The signs of these effects are clearly dose related. The more the mother drinks, the more handicapped the child is likely to be, and the greater the risk in general to the child.

The type of alcohol taken does not seem to matter—beer, wine, distilled alcohol—but it is the total amount that is taken. And when it is taken in the pregnancy—clearly organ systems are more vulnerable at different times of the pregnancy.

I might ask you to turn to table I which lists all of the abnormalities currently known to be part of the fetal alcohol syndrome. Let me just highlight the ones that are most important.

The growth abnormalities, the facial abnormality, we talked about, congenital heart disease is very common in these children, and they show a number of functional abnormalities. Newborns suck very poorly and therefore they are unable to eat properly and the children show developmental delays. There is some evidence that attention deficit disorders, learning disabilities, hyperactivity, are more common in children as a result of alcohol.

The frequency of this is really clearly not known. I understand this morning you were told that the CDC estimates that the frequency is between one in every 1,800 to 2,400 live births. I personally think that that is too low and represents underreporting. I think those of us working in the field feel a number of 1 to 2 per thousand live births is probably more realistic for the fetal alcohol syndrome; and that between 3 to 5 per thousand live births for the fetal alcohol effects. This makes fetal alcohol syndrome the third most common cause of mental retardation, and we all believe that it is now more common than Down's syndrome.

There are a number of confounding variables that make it difficult to come up with an exact frequency incident figure. Very clearly, other factors such as smoking, poor nutrition, vitamin deficiency, use of other drugs such as marihuana, all seem to increase the risk of the child being abnormal when the mother is drinking alcohol. Socioeconomic class is also important.

A recent study at the Boston City Hospital, which is an intercity urban hospital, has shown consistently work that we started 10 years ago, and is being continued now by others, that the rate of alcoholism in the young women there is 10 percent of the clinic population. And in their recent study of 1,690 mother-infant pairs, they had 31 cases of the fetal alcohol syndrome, which by my calculations come out to be 18 per thousand. So I think there is a great variability.

The majority of children show only some of these abnormalities, and unfortunately there are no laboratory tests that can diagnose this disorder, nor is there any present capability of identifying abnormal fetuses by amniocentesis.

More recent work on moderate alcohol use is somewhat disturbing. A number of different studies carried out in this country and in other countries show that small amounts of daily consumption of alcohol, as little as 2 ounces of 100-proof whiskey or 1 ounce of absolute alcohol, is associated with lower birth weight in the children, and increased rates of miscarriage. It does not appear that the children show these birth defects when the mother drinks moderately. Again, the concurrent use of marihuana seems to increase the risk to the fetus.

I should point out that at the present time safe levels of alcohol intake during pregnancy are yet to be determined. At the present time, those of us working in the field recommend that pregnant women abstain from alcohol during the pregnancy and for the month prior to conception, if the pregnancy is going to be planned.

We also advise women who have in fact come in and have commented that they have had a glass or two of wine a week. At the present time, there is no evidence that occasional alcohol intake is harmful to the fetus, but simply in trying to maximize the opportunities for developing a normal baby we would certainly recommend this. We make similar recommendations to the nursing mothers because alcohol goes into breast milk.

Alcohol passes rapidly from the maternal circulation through the placenta into the fetus, and there is some interesting work that has shown if a pregnant woman is given 1 ounce of alcohol, her liver will clear this in an hour and it will be going from her system, when in 15 minutes the baby's blood alcohol level is the same as the mother's, but the baby lacks the enzyme to break down the alcohol, and measurable amounts of alcohol have been found in these fetuses 12 to 16 hours later. It is then excreted into the amniotic fluid, reswallowed by the baby and recirculated around. So a simple 1 ounce of alcohol remains in the baby for really a long period of time, and this is why we are recommending some of these things that sound perhaps a little extreme.

To give you an idea in terms of some of the statistics on women and alcohol, the NIAAA reported in 1950 that one out of every eight alcoholics was a woman. In 1982, they say one out of every three alcoholics is a woman. And excessive drinking is rising very rapidly in women. The highest rate of rise is in the age group 21 to 29; the second highest is in the teenage years. These are precisely the ages of highest childbirth.

The use of alcohol among girls, young girls and young women, is approaching men, and in some cases probably people think it is getting closer to one on one. Reliable data are hard to come by. There is still some stigma attached to this, and women tend to drink secretly in their home rather than in bars and so forth, so they don't come to attention by alcoholic-related car accidents, work-related problems, as often as men do.

I think what I would like to focus on is some of the prevention strategies that I think are important to be considered. One thinks of children-oriented preventive things. I think it is important that these children be identified at birth that they are children clearly at risk.

One of the major problems these children show is the actual rejection of food. They are very difficult children to feed. We have video tapes of children who actually extrude food with their tongue as you try to put it in. They are very poorly coordinated in their sucking and swallowing motion, suck more actively than normal and can't swallow, and milk comes out of their mouths. And they are very difficult children in general.

And if the mother has an alcohol problem, she sometimes has a poor self-image. She feels rejected her baby is not eating and not growing; she is a bad mother. Oftentimes, she will then start drinking heavily again. It becomes a very difficult problem. These women require and these children require a great deal of outreach and intervention. They should be seen frequently by a nutritionist.

It is important to have nurses go into the home; that they are sent early to intervention programs so they can get physical therapy, occupational therapy, for their physical abnormalities, and that the mother gets a lot of support. They often aren't very good at coming for appointments and so there is a lot of outreach that needs to be done for these children.

I think in terms of trying to prevent the problems with the women, there are two sides that are particularly useful. One is the prenatal clinic, and the other is family planning clinics. I think that too often the people who treat alcohol problems and the obstetricians and prenatal clinics don't get together. I think there should be more coordination and that there should be an alcohol counsel in any large prenatal clinic so that when women are identified, they can, in fact, get some help on the spot.

I frequently will get a call from an obstetrician saying, "I have a 6-week pregnant woman in my office. It seems she is drinking a lot. What do I do now?" We are able to refer these women for some counseling. The women have to be asked about their drinking habits when they are pregnant or when they see doctors. I think doctors oftentimes are embarrassed to ask some of these questions. If you don't ask the questions, you are not going to find out; you are not going to prevent the problem.

I think the other area for prevention, which is one that we have been focusing on, is in the school. I think that getting to women in prenatal clinics once they are pregnant is fine, but you know you have already missed the boat for that particular pregnancy. I think it is vital that young girls 13 and up learn as a part of their general health programs that alcohol intake during pregnancy is contraindicated. Teenagers don't think of themselves as being in the childbearing years, but you know that is not the case. Twenty percent of them will be pregnant by the time they reach age 20. Many of them don't eat well and don't take very good care of themselves.

We at the Shriver Center for Mental Retardation in Waltham, Mass., have been designated the New England resource for fetal alcohol syndrome treatment and prevention, and we have developed a number of educational programs, video tapes, lectures, brochures, et cetera, which we provide free to educational institutions, professional physicians, et cetera. And we also have served as resource. We have a list of all of the treatment centers in New England so that we can, in fact, on the telephone, refer people for services.

I think it would be important to set up more regional centers like this. I know there is a group in Seattle doing the same kind of thing. I am really not sure about the rest of the country.

I also think that it is important that women with alcohol problems be treated differently from men. At the present time, most women are treated as an add-on to men's programs. For instance, in Massachusetts there is no detoxification center for women. My understanding is there are three or four beds set aside in a large dormitory-type room which can be used for women, pregnant or not, who need detoxification.

I think that is an intolerable situation. I can't imagine anyone who would voluntarily go into that kind of situation. I think there need to be more programs specifically set up for women and young women, and that focus on some of these preventive aspects.

[Prepared statement of Dr. Eileen Ouellette follows:]

PREPARED STATEMENT OF EILEEN M. OUELLETTE, M.D., DIRECTOR, UNIVERSITY AFFILIATED FACILITY AT THE EUNICE KENNEDY SHRIVER CENTER, WALTHAM, MASS.; ASSISTANT PROFESSOR OF NEUROLOGY, HARVARD MEDICAL SCHOOL; ASSISTANT NEUROLOGIST, MASSACHUSETTS GENERAL HOSPITAL, BOSTON, MASS.

DEFINITION

Fetal Alcohol Syndrome (FAS) refers to a series of effects seen in children of women who chronically drink alcohol to excess during, and possibly prior to, pregnancy.[1-6] Minimum criteria for the diagnosis of FAS are:

(1) Prenatal and/or postnatal growth retardation, with weight, length, and/or head circumference below the tenth percentile;

(2) Central nervous system imvolvement, with neurologic abnormality, developmental delay or intellectual impairment;

(3) Facial dysmorphology (birth defects) with at least two out of three signs: (a) Microcephaly (small brain); (b) Microphthalmia (small eyes) and/or short palpebral fissures (the horizontal length of the eyes); and (c) Poorly developed philtrum (the distance from the base of the nose to the upper lip), thin upper lips, and/or flattening of maxillary area.

The spectrum of clinical features currently known is shown in Table I.

Fetal alcohol Effects (FAE) refers to any abnormalities seen in children as a result of alcohol use by women during pregnancy.[8-10]

FREQUENCY

There were 3 million, 704 thousand babies born in the United States in 1982. FAS is estimated to occur between 1 and 2 per thousand live births for the full constellation of features (3,700 to 7,400 babies), with the frequency of partial expression at possibly between 3 to 5 per thousand live births (11,100 to 18,500 babies). It is the third most common cause of mental retardation and is more common than Down syndrome.[9-11] FAS is totally preventable.

Information is still lacking concerning the full scope and gravity of the ill effects on the fetus and infant of chronic maternal alcohol abuse prior to and during pregnancy. Effects produced range from mildly impaired to profoundly afflicted children and some fatalities have been reported. It is unknown how many children's lives have been permanently afflicted by excess alcohol use in their mothers. The risk of producing an abnormal child for a mother with alcohol abuse is unknown. Some evidence exists that children are more at risk for abnormalities with each successive pregnancy in which the mother continues to drink heavily.

The majority of children show only some of the abnormalities described. Alcohol embryopathy should be suspected when growth retardation and/or congenital abnomalties are present in a child and a careful history of ethanol abuse should be elicited from the mother. Unfortunately, there are no laboratory tests which are diagnostic of this disorder, nor is there any present capability of identifying abnormal fetuses by amniocentesis.

MODERATE ALCOHOL USE

Studies on moderate drinking during pregnancy, equivalent to a daily consumption of 2 oz. of 100-proof whiskey, is associated with lower birth weight in offspring and increased prematurity rates.[13-16] Concurrent use of marijuana while pregnant may increase the risk of developing FAS.[17]

Safe levels of alcohol intake during pregnancy, if any, have yet to be determined. At the present time, we recommend that pregnant women abstain from alcohol, but advise women that an occasional alcoholic beverage has not been found to be harmful to the fetus. Similar recommendations are made to nursing mothers.

MATERNAL/CHILD EFFECTS OF ALCOHOL

Alcohol passes rapidly from the maternal circulation to the fetus and assumes approximately the same concentration as in maternal blood.[18-19] Alcohol levels within the fetal circulation fall more slowly than in the maternal circulation, so that detectable levels of alcohol are still present in the fetus after the alcohol has been totally cleared from the maternal circulation.[20-21] Not only does alcohol enter the fetal circulation but it is excreted into the amniotic fluid where it remains in essentially the same concentration for several hours until slowly being cleared. Changes are seen in fetal acid-base balance, cerebral function and metabolism. Alcohol has also been found to reach human milk in a similar concentration to that in peripheral maternal blood, decreasing together with decreasing ethanol content of the blood.

WOMEN AND ALCOHOL

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) reports that in 1950 one in every 8 alcoholics was a woman. In 1982, one in every 3 alcoholics was a woman.[22] Excessive drinking is rising at a rapid rate. The highest proportion of heavy drinkers among women is between the ages of 21-29, the age of peak reproductive years.[23] The second highest is in the teenage years. Current NIAAA statistics report that there are 2.25 million woman problem drinkers and 3 million teen problem drinkers in the U.S.[24]

The use of alcohol among girls and among women is approaching that of boys and men. Reliable data concerning alcoholism in women are difficult to come by as the female alcoholic has a greater tendency to drink secretly in the privacy of her home and therefore comes to professional attention later than the male alcoholic, who often is identified through poor work performance or automobile accidents.

Recent studies show that all women tend to decrease their alcohol intake during the early months of pregnancy, presumably from a combination of factors.

PREVENTION STRATEGIES

1. Child oriented

It must be stressed again that the Fetal Alcohol Syndrome and its spectrum of abnormalities are a totally preventable cause of growth abnormalities, congenital malformations and mental retardation. Intense and extensive preventive strategies should be undertaken as there is no known way to reverse or reduce the effects of alcohol on the fetus once they have occurred. Once a baby has been born with signs of FAS, early identification of the problem, treatment for specific clinical findings, infant stimulation and close attention to nutritional problems are vital.

In our experience, much of the postnatal growth retardation seen in these children is due to their active rejection of food. Videotapes which we have made indicate that the children have increased but uncoordinated sucking and swallowing movements coupled with extrusion movements of the tongue, so that their intake in food is less than adequate and feeding times are prolonged. Even highly experienced foster mothers find these children extremely difficult to feed. Generally, feeding problems are significant for the first year of life and gradually improve so that by the time the children are 3 to 4 years of age they are consuming a more adequate diet, although they continue to be highly selective in their food preferences.

2. Pregnant women and mothers

Two sites are especially useful in the identification of women of child bearing age who have alcohol related problems. Family planning and prenatal clinics are ideal locations for educational programs and places where women with alcohol problems should be identified.[25]

Questions about alcohol use should be routinely asked of women at the first prenatal visit. A brief questionnaire developed by Rosett et al. has been found to be useful in identifying moderate and heavy drinkers in a nonthreatening and non-time consuming manner.[26, 27] [Table II]

We and others have found that the prenatal clinic is an ideal site for initiating intervention in women previously unidentified as having alcohol related problems.[25, 28] Women so identified should be referred to alcohol treatment centers for additional counseling and support. The women are generally highly motivated to alter their drinking behavior in order to produce offspring with the least possible risk. Their repeated associations over several months with health care deliveries assist them to form therapeutic relationships. Heavy drinking women who stop drinking during pregnancy have a good chance of delivering a normal child. Although no improvement in the risk of congenital malformations could be expected due to their appearance early in the pregnancy, the risk of prematurity and growth retardation is lessened.[6, 24]

In the postnatal period, there is an increased risk of recidivism. The impetus for modifying behavior is often less after the baby has been born. The increased stress of taking care of an infant may cause the mother to revert to previous drinking patterns, particularly if the infant has problems, such as poor feeding, sleeping, and restlessness.

The importance of outreach efforts and home visits during this period cannot be overemphasized. Women often find it more difficult to keep appointments outside the home in the postnatal period but welcome visits by a therapeutic nurse practitioner, alcoholism counselor or other therapist. Women should have a telephone number to call 24 hours a day in case significant problems arise. Referral to strong supportive programs, such as Alcoholics Anonymous, are important through the prenatal and postnatal periods.

3. Educational programs

The Eunice Kennedy Shriver Center for Mental Retardation in Waltham, Massachusetts, has been designated as a New England Regional resource for the prevention and treatment of the fetal alcohol syndrome. We have developed a variety of educational programs for health care and other professionals, alcohol treatment centers, families, including foster parents, teachers, junior high, high school and college students, and the public at large. The goal of these programs is to identify and refer women and children at risk. It is extremely important that practicing physicians and house officers in the fields of obstetrics and gynecology, family practice and pediatrics be aware of the harmful effects of maternal alcohol abuse on offspring, that they seek and recognize those at risk, that they become skilled in ascertaining drinking histories, and that they have sufficient knowledge of local resources to refer people for assistance. Scientific presentations, publication of articles in professional journals, and participation in hospital departmental grand rounds are all useful means of providing this type of education.

Nurses, particularly those employed in prenatal clinics and newborn nurseries, midwives, staffs of family planning agencies, social workers, psychologists, alcoholism counselors and teachers are frequently the first to identify families with alcohol related problems. Participation in workships, health fairs and inservice training sessions has been very effective in new case findings.

Families themselves, including foster families and mothers in alcohol treatment centers and halfway houses benefit not only from individual therapy but gain knowledge and skills from being given factual information in a group setting. This format increases their understanding and recognition of common problems and assists them to ask questions of their individual physicians and other therapists.

It should be stressed that women in halfway houses comprise a special audience. They are often in different states of recovery and guilt. Prior staff preparation and presentation of child related information in a nonthreatening and supportive fashion is essential. In some cases, it is wiser for individuals to defer participation in some of the FAS educational programs until they themselves are further along in their recovery.

Another important part of our educational programs is our participation in school health curricula. Our FAS program director has prepared an educational package consisting of a slide tape, verbal presentation and question and answer session, which is now part of the Health Care Curriculum in a number of local schools.

A special program has been developed for pregnant teenagers, who continue to attend high school. The focus is on the use and abuse of alcohol as part of general health issues. A list of common non-prescription medications containing alcohol is provided to them to make them realise the need to be aware of the contents of everything they ingest while pregnant.

A final form of educational program is that of increasing public awareness. Public service announcements of 30 seconds each are routinely aired on local and regional TV stations. Brochures have been developed for placement in physicians offices, family planning agencies, prenatal clinics, libraries, schools, churches, alcohol treatment agencies, women's groups and treatment centers. Others have utilized marriage license bureaus, and diaper services to educate the general public about FAS.[28]

SUMMARY

The re-identification of the risk of maternal alcohol use during pregnancy and the recognition of the effects of alcohol on fetal development are only ten years old. Much remains to be learned about the cause and scope of the problem. Unlike genetic disorders, it is totally preventable. Early identification of those at risk and increased public awareness continue to be our best weapons in combatting this important public health program.

TABLE I.—CLINICAL FEATURES OF FAS: TABLE OF ABNORMALITIES

Growth abnormalities; Prematurity; Intrauterine growth retardation; Postnatal growth retardation, short stature, diminished weight.

Craniofacial anomalies: Microcephaly; eye abnormalities, epicanthal folds, telecanthus, short palpebral fissures, corneal opacity, ptosis, high myopia, strabismus tortuosity of retinal vessels; flattened nasal bridge; abnormally formed ears; maxillary hypoplasia; narrow vermilion border of upper lip; small mandible; cleft palate.

Joint and limb malformations: Limitation of elbow extension; phalangeal anomalies, small nails, clinodactyly; abnormal palmar creases; dislocated hips.

Cardiac abnormalities: atrial septal defects; ventricular septal defects; tetralogy of fallot; patent ductus arteriosus; aortic arch interruption type A; peripheral pulmonic stenosis.

Renal anomalies: hydronephrosis; single kidney; hypoplastic kidneys.

Functional abnormalities; neonatal, poor suck, hypotonia, tremulousness.

Postnatal: developmental delay, mental retardation, poor gross motor coordination, poor fine motor coordination, learning disabilities, hyperactivity, decreased attention span.

Other findings: Hydrocephalus; neural tube defects; single umbilical artery; Noonan syndrome; Klippel-Feil anomaly; capillary hemangiomata; abnormal external genitalia; accessory nipples; adrenal cortical carcinoma; spastic diplegia.

TABLE II

10—QUESTION DRINKING HISTORY FOR PRENATAL USE—
Beer:
How many times per week ———
How many cans each time ———
Ever drink more? ———
Wine:
How many times per week ———
How many glasses each time ———
Ever drink more? ———
Liquor:
How many times per week ———
How many drinks each time ———
Ever drink more? ———
Has your drinking changed in the last year? ———

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Dr. Greenspan. Thank you. It is an honor to be here and have an opportunity to discuss the prevention of health and mental health problems in infants, young children, and their families.

First, I would like to thank the Honorable George Miller, chairman; Dan Marriott, ranking minority member; and William Lehman, chairman of this Task Force on Prevention Strategies, for focusing the country's attention on children, youth, and families and on prevention as one of three main priority areas.

I am a child psychiatrist and Chief of the Clinical Infant Research Unit in the intramural research program, at the National Institute of Mental Health. A major area of my professional interest is on the adaptive and maladaptive emotional development of infants, children and their families.

The following summary comments about emotional development will reflect my own views as a clinician and a researcher.

First, I would like to emphasize that we know a great deal about normal emotional and intellectual development in infants and young children, enough to do a great deal now, even without further research. We probably know more about infants and young children's normal emotional development than any other time in the life cycle, including adulthood.

An enormous body of research, for example, documents development beginning prenatally and postnatally such things as how the baby uses his senses to perceive his environment, to make visual and auditory discriminations, to respond favorably to pleasure, emotional warmth, and security, and to respond unfavorably to deprivation of emotional and sensory experiences and to erratic overstimulation, which overwhelms early integrative capacities.

One, the healthy infant continually increases his capacity to process information and enter into ever more complex emotional, social, and cognitive patterns during the early years.

Two, beginning with the first few months of life, we can now chart the emotional, social, and cognitive milestones, much as we do the neuromotor milestones of sitting, crawling, walking, and talking. We can also chart disturbances or departures from these expected developmental patterns, and identify some of the constitutional and environmental factors associated with these disturbances.

For example, during the first 2 months, healthy infants increasingly have moments of a calm, but alert states where they practice using their sense of vision, hearing, smell, and motion. In contrast, hyperexcitable infants have rigid muscles, arch their backs, look away rather than toward their care givers, and overreact to normal touch or sounds. Hyporeactive infants seem to shut down and evidence poor muscle tone; they do not alert or brighten to a variety of sensory and social overtures.

Some infants appear to begin life with maladaptive patterns. In such instances, even competent families may need guidance to figure out how to find just the right pattern of rocking, vocalizations and stroking to help their infants learn to be calm, alert, attentive states. Some infants begin competently but lose their early adaptive capacities. In these situations clinically we have observed either unavailable or overly intrusive, chaotic care giving patterns.

Regardless of whether the basis for the early maladaptive patterns appears to be constitutional or a result of early experiences, on a case-by-case basis, we observed that providing special patterns of care helped the infants return to competent developmental patterns.

By 2 to 4 months, we can observe infants who evidence that enraptured emotional engagement where they seem fascinated with the human world. In response to their caregiver's smiling, talking face, they smile back, listen, and even move their arms in synchrony to their caregiver's voice. The infant's pleasurable emotions and the strong investment of the caregiver appear to motivate the infant to use and organize his senses and his sensory motor organization. In contrast, we also observe infants who are already unresponsive to the human world, evidencing flat or despondent emotional expressions.

They may look away rather than toward their caregivers and respond to the human voice with panic rather than comfort. Secondary sensory motor delays and severe communication problems are not uncommon. Here too, we have worked with cases where there were constitutional vulnerabilities, and others where the main problems were in the caregiving pattern and still others where both factors were present. Most encouragingly, special patterns of care tended to reverse the maladaptive behavior. It would appear that the infant has great plasticity and recovery power if we provide him or her the opportunity for favorable development.

As the infant progresses, we can observe infants who learn cause and effect interactions; that is, the world is lawful, and complex motor and social skills. Eventually by 18 months to 2 years they learn to use ideas to guide language, motility, imagination, and eventually to think and plan. In contrast, we observe infants whose behavior remains random and chaotic, who never develop functional complex social patterns, and the functional use of ideas.

They eventually evidence language delays and deficits in thinking, imagination and such basic personality functions as knowing what is real from pretend, controlling impulses and mood, and focusing attention to concentrate and learn. We have been impressed by how important the second year of life is for the development of higher level emotional and conceptual skills. Many toddlers develop competently and are even precocious motorically until 15 to 16 months of age. However, we feel that because of a lack of appropriate experiences, they do not fully make the next step of using ideas to label and interpret feelings, to think, plan, and learn new conceptual skills that are essential for school and eventual participation in an increasingly technological society. Special programs at this age may have enormous payoff for many of these children.

Three, most importantly, there is now a great deal of evidence from case studies and some emerging evidence from large group studies that early identification and preventively oriented interventions can effectively reverse early maladaptive patterns and promote healthy development.

The elements we feel an intervention program must contain are:

A focus on the interactions of the multiple aspects of development, including physical-neurological, cognitive, emotional, social, and familial. Offering preventive intervention to the infant and not the family or the intellectual lags and not emotional and social limitations ignores the complexity of human beings and their families.

Preventive intervention approaches must be tailored to the individual differences in infants, young children and their families.

The integration of three levels into the preventive intevention approaches are necessary.

One, attention to concrete needs for survival, food, housing, care.

Two, an ongoing human relationship with a key member of the intervention team.

Three, availability of specialized clinical, diagnostic and preventive intervention approaches for complex problems such as infants with sensory hypersensitivities to touch or sound or parents with depressive illness or other disturbances.

Four, there are especially challenging families referred to as multi-problem and more recently by our research group as multirisk. Over 30 years ago it was estimated that they constituted 5 to 10 percent of the population but used 50 to 75 percent of all the public health, mental health and social services. No recent data on this population exist. One can only guess that this pattern may be even more extreme now.

In case studies, the children in these families were observed to have severe problems in such basic personality functions essential for school and later work and family life, as knowing the real from the pretend, controlling impulses and mood, and focusing attention and concentration in order to learn and interact with others. We have found that many of the emotional and cognitive disturbances of these children can be identified as early as the first months of life.

Even families with more than three generations of marginal coping and a history of distrust of traditional services can be involved in an ongoing preventive intervention program. Most importantly, on a case-by-case basis, we have been able to show that the at-risk infants, young children, and their families can be helped to competent functioning.

The intergenerational nature of these patterns are important. Often the multirisk mothers begin their child rearing as teenagers and they and their children do worse with each subsequent pregnancy. These mothers describe a similar pattern with their own mothers. And in all likelihood, their children will continue these patterns. We have observed in our cases that by helping a mother and family with one child, not only does that child and the whole family do better, but the next child does better. It appears that a negative cycle of geometric proportions is broken and a postive one begun.

Five, the implications for a national health, mental health, and educational prevention policy should also be considered. With 13 percent of our school-age children receiving special services and, as a clinical hunch, another 15 percent who could probably benefit from such services, we must rethink our basic philosophy on such fundamental notions as equal opportunity and an education for all our children. When children enter school already handicapped in cognitive or emotional functioning, they do not have an equal opportunity.

In addition, they have critical educational lags. Education, health, and mental health care must begin at the beginning, when the brain is growing most rapidly. The brain grows to two-thirds of its adult size by the time a child is three. In my view, infants require phase specific nutriments of a biological, that is, nutrition, and experimental—that is, emotional, physical and cognitive experiences nature geared to their own individual differences and stage specific requirements.

While some infants have unusual capacities to find the nutriments, the nutriments must be available in the proximity. These nutriments are essential for the attainment of critical milestones in the education, health, and mental health of our infants in the first 3 years of life. These milestones include, as discussed earlier, learning to: One, regulate one's body and use one's senses to perceive the world; two, form distinctly human emotional relationships; three, interact in a cause and effect or purposeful manner; four, organize complex cognitive and emotional patterns; five, construct ideas to guide language, behavior, and feelings; and six, to think and plan.

All these milestones which occur before children have access to school are critical to their health, mental health, and education.

The following sections will briefly amplify each of the above points. Normal emotional and social development in infancy: While there are no large-scale studies of infants and young children's affective patterns at different ages to partition the range of emotional patterns in the general population, there is extensive literature on the emotional development of presumed normal infants. Interestingly, during the past 15 years there has been considerably greater documentation of normal emotional development in infants than probably any other age group.

It is now well documented that the infant is capable, even at birth and/or shortly thereafter, of organizing experience in an adaptive fashion. He or she can respond to pleasure and displeasure—Lipsett, 1966; change behavior as a function of its consequences—Gewirtz, 1965, 1969; form intimate bonds and make visual discriminations—Klaus and Kennell, 1976; Meltzoff and Moore, 1977; organize cycles and rhythms, for example, sleep-awake, alertness states—Sander, 1962; evidence a variety of affects or affect proclivities—Tomkins, 1981; Izard, 1978; and Ekman, 1972; and demonstrate organized social responses in conjunction with increasing neurophysiologic organization—Emde, Gaensbauer, and Harmon, 1976; the infant from the early months demonstrates a unique capacity to enter into complex social and affective interactions—Stern, 1974a, 1974b, 1977; Brazelton, 1974.

It is interesting to note that this empirically documented view of the infant is, in a general sense, consistent with Freud's early hypotheses, 1911, and Hartmann's postulation, 1939, of an early undifferentiated organizational matrix. That the organization of experience broadens during the early months of life to reflect increases in the capacity to experience and tolerate a range of stimuli, including responding in social interaction in stable and personal configurations, is also consistent with recent empirical data—Emde et al., 1976; Sroufe, Waters and Matas, 1974; Escalona, 1968; Stern, 1974a, 1974b; Sander, 1962; Brazelton, Koslowski and Main, 1974; Murphy and Moriarty, 1976.

That increasingly complex patterns continue to emerge as the infant further develops is indicated by complex emotional responses such as surprise—Charlesworth, 1969, and affiliation, wariness and fear—Ainsworth, Bell and Stayton, 1974; Bowlby, 1969; Sroufe and Waters, 1977, observed between 7 and 12 months; exploration and refueling patterns—Mahler, Pine and Bergman, 1975; behavior suggesting functional understanding of objects; Werner and Kaplan, 1963, observed in the middle to latter part of the second year of life and the eventual emergency of sumbolic capacities—Piaget, 1962; Gouin-Decarie, 1964; Bell, 1970.

In the above studies, there is a consensus—and there are no dissenting studies—that by 2 to 4 months of age at the latest, and often much earlier, healthy infants are capable of responding to their care giver's faces, smiles, and voices with brightening or altering and, often, with a smile and reciprocal vocalizations, suggesting positive affect, as well as other reciprocal responses. Furthermore, the infant care giver's interaction patterns become progressive characterized by more complex social interaction as development proceeds.

Two, comparison of adaptive, normal, and maladaptive developmental patterns in infancy. Psychopathology in infancy: The study of psychopathology in infancy is a new area even though the historical foundation for identifying disturbances in the early years of life is very impressive. Constitutional and maturational patterns which influences the formation of early relationship patterns were already noted in the early 1900's with descriptions of babies of nervous inheritance who exhaust their mothers—Cameron, 1919, and infants with excessive nerve activity and a functionally immature nervous system.

Winnicott, who as a pediatrician in the 1930's began describing the environment's role in early relationship problems—1931, was followed in the 1940's by the well-known studies describing the severe developmental disturbances of infants brought up in institutions or in other situations of emotional deprivation—Lowrey, 1940; Hunt, 1941; Bakwin, 1942; Bowlby, 1952; and Spitz, 1945. Spitz's films resulted in laws in the United States prohibiting care of infants in institutions.

The role of individual differences in the infant based on constitutional maturational and early interactional patterns that is, i.e., nervous infant described by Cameron 1919 and Ford 1905 in the early 1900's again became a focus of inquiry, as evidenced by the observations of Burlingham and A. Freud—1942; Bergman and Escalona's descriptions of infants with unusual sensitivities—1949; Escalona, Heide, Moriarity and Murphy's overview—1976; Murphy's vulnerability index—1976; Chess and Thomas' temperament studies—1977; Cravioto and DeLicardie's descriptions of the role of infant individual differences in malnutrition; and the impressive emerging empirical literature on infants—Sander, 1962, Brazelton, 1974; Lipsitt, 1966; Stern, 1974; Emde, 1976; Gewirtz, 1961; and Reingold, 1961, 1963.

More integrated approaches to understanding disturbances in infancy has been emphasized in descriptions of selected disorders and very insightful clinical case studies, that is, Fraiberg, 1970; Provence, 1979, in press; Williams, et al., in press.

In order to foster preventive efforts, we at the Clinical Infant Research Unit, intramural research program, National Institute of Mental Health, undertook a study of normal and disturbed developmental patterns in infancy in order to develop a more comprehensive classification of adaptive and maladaptive infant and family patterns. Below is a chart summarizing the adaptive and maladaptive infant and family patterns followed by a brief description of these patterns. See Greenspan, 1979; Greenspan, Lourie and Nover, 1979; Greenspan and Lourie, 1981; Greenspan, 1981 for a more detailed description of these patterns.

[The chart follows:]

Dr. **Greenspan**. The capacities described by these stages are all present in some rudimentary form in very early infancy. The sequence presented suggests not when these capacities begin, but when they become relatively prominent in organizing behavior and furthering development. In this classification, the first stage is the achievement of homeostatis, i.e., self-regulation and emerging interest through the senses in the world—sights, sounds, smells, touch, et cetera. Once the infant has achieved some capacity for regulation in the context of engaging the world, and central nervous system maturation is increasing--between 2 and 4 months of age—he becomes more attuned to social and interpersonal interaction. He is more able to respond to the external environment and to form a special relationship with the significant primary care givers. Thus, a second, closely related stage is that of forming a human attachment.

If an affective and relatively pleasurable attachment—an investment in the human, animate world—is formed, then with growing maturational abilities, the infant develops complex patterns of communication in the context of this primary human relationship. Parallel with development of the infant's relationship to the inanimate world where basic schemes of causality—means/ends relationships, Piaget, 1972—are being developed, the infant becomes capable of complicated human communications—Brazelton, et al., 1974; Stern, 1974a; Tennes, et al., 1972; Charlesworth, 1969.

When there have been distortions in the attachment process—e.g., if a mother responds in a mechanical, remote manner and/or projects some of her own dependent feelings onto her infant, the infant may not learn to appreciate causal relationships between people at the level of compassionate and intimate feelings. This can occur even though causality seems to be developing in terms of the inanimate world and the impersonal human world. We have observed infants who are differentiated in the assertive impersonal domain of human relationships but who are relatively undifferentiated in the intimate, pleasurable domain.

Causal relationships are established between the infant and the primary care giver as evidenced in the infant's growing ability to discriminate significant primary care givers from others. He also becomes able to differentiate his own actions from their consequences, affectively, somatically, behaviorally, and interpersonally. Usually by 8 months of age or earlier, the process of differentiation begins along a number of developmental lines; for example, with sensorimotor integration, affects, relationships.

A third stage, therefore, may be formally termed somatopsychologic differentiation to indicate processes occurring at the somatic (e.g., sensoriomotor) and emerging psychological levels.

In this context, psychologic refers to higher level mental processes characterized by the capacity to form internal representations or symbols as a way to organize experience. While schemes of causality are being established in the infant's relationship to the interpersonal world, it is not at all clear whether these schemes exist at an organized representational or symbolic level. Rather, they appear to exist mainly at a somatic level (Greenspan, 1979), even though we do observe the precursors of representational capacities. Some are perhaps even prenatally determined (Lourie, 1971).

With appropriate reading of cues and systematic differential responses, the infant's or toddler's behavioral repertoire becomes complicated and communications take on more organized, meaningful configurations. By 12 months of age, the infant is connecting behavioral units into larger organizations as he exhibits complex emotional responses such as affiliation, wariness, and fear (Bowlby, 1969; Ainsworth et al., 1974; Sroufe and Waters, 1977).

As the toddler moves farther into the second year of life, in the context of the practicing subphase of the development of individuation [Mahler et al., 1975), there is an increased capacity for forming original behavioal schemes (Piaget, 1972) and imitative activity and intentionality.

A type of learning through imitation evidenced in earlier development now seems to assume a more dominant role. As imitations take on a more integrated personal form, it appears the toddler is adopting or internalizing attributes of his care givers. To describe these new capacities, it is useful to consider a fourth stage, that of behavioral organization, initiative, and internalization.

As the toddler moves into the end of the second year, with further CNS maturation, we notice an increased capacity to form and organize mental representations, i.e., ideas. Internal sensations and unstable images become organized in a mental representational form which can be evoked and is somewhat stable (Piaget, 1972; Bell, 1970; Gouin-Decarie, 1965). While this capacity is initially fragile (i.e., between 16 and 24 months), it soon appears to become a dominant mode in organizing the child's behavior, and a fifth stage can be documented, that of forming mental representations or ideas.

As a clarification of related concepts, it should be pointed out that the capacity for "object permanence" is relative and goes through a series of stages (Gouin-Decarie, 1965); it refers to the toddler's ability to search for hidden inanimate objects. Representational capacity refers to the ability to organize and evoke internal organized multisensory experiences of the animate object. The capacities to represent animate and inanimate experiences are related and depend both on CNS myelination and appropriate experiences. The process of "internalization" may be thought of as an intermediary process. Internalized experiences eventually becomes sufficiently organized to be considered representations.

At a representational level, the child again develops his capacities for elaboration, integration and differentiation. Just as causal schemes previously were developed at a somatic and behavioral level, now they are developed at a representational level. The child begins to elaborate and eventually differentiate those feelings, thoughts, and events that emanate from himself and those that emanate from others. He begins to differentiate what he experiences and does from the impact of his actions on the world. This gradually forms the basis for the differentiation of "self" representations from those which embody the external world, animate and inanimate, and also provides the basis for such crucial personality functions as knowing what is real from unreal, impulse and mood regulation, and the capacity to focus attention and concentrate in order to learn and interact.

The capacity for differentiating internal representations become consolidated as object constancy is established (Mahler et al., 1975). In middle childhood, representational capacity becomes reinforced, with the child's ability to develop derivative representational systems tied to the original representation and transform them in accord with adaptive and defensive goals. This permits greater flexibility in dealing with perceptions, feelings, thoughts, and emerging ideals. Substages for these capacities include representational differentiation, the consolidation of representational capacity, and the capacity for forming limited derivative representational systems and multiple derivative representational systems (structural learning [Greenspan, 1979]).

At each of these stages in varying degrees, pathologic as well as adaptive formations are possible. These may be considered as relative compromises in the range, depth, stability, and/or personal uniqueness of the experiential organization consolidated at each stage. The infant can form adaptive patterns of regulation in the earliest stages of development. His internal states are harmoniously regulated and he is free to invest himself in the animate and inanimate world, thereby setting the basis for rich emotional attachments to his primary caregivers.

On the other hand, if his regulatory processes are not functioning properly and he cannot maintain internal harmony in the context of being available to the world, the infant may withdraw. From relatively minor compromises such as a tendency to withdraw and/or be hyper-excitable under stress, to a major deviation such as an overwhelming avoidance of the animate world, we can observe the degrees to which the infant, even in the first months of life, achieves a less-than optimal adaptive structural organization.

Thus, the early attachments can be warm and engaging, or shallow, insecure, and limited in their affective tone. In the early reciprocal relationships, we can observe differences between an infant who reads the signals of the caregivers and responds in a rich, meaningful way to multiple aspects of the communications (with multiple affects and behavioral communications), and one who can respond only within a narrow range of affect; for example, protest, or who can respond at all in a contingent or reciprocal manner; for example, the seemingly apathetic, withdrawn, and depressed child who responds only to his own internal cues.

As the toddler, optimally, becomes behaviorally more organized and complex patterns appear which reflect originality and initiative in the context of the separation and individuation subphase of development, we can observe those toddlers who manifest this full adaptive capacity. They may be compared with others who are stereotyped in their behavioral patterns—reflect no originality or intentionality—who remain fragmented, never connect pieces of behavior into more complicated patterns; or who evidence polarities of affect, showing no capacity to integrate emotions, for example, the chronic negativistic aggressive toddler who cannot show interest, curiosity, or love.

As a capacity for representational organization is reached, we can distinguish the child who can organize, integrate, and differentiate a rich range of affective and ideational life from one who remains either without representational capacity or undifferentiated (i.e., deficits with reality testing, impulse control, focused concentration, or who may form and differentiate self and object representations only at the expense of extreme compromises in the range of tolerated experience (for example, the schizoid child who withdraws from relationships). Similar adaptive or maladaptive structural organizations can be observed in later childhood—the triangular phase—latency, and adolescence.

A more detailed discussion of this framework, including principles of prevention and intervention, is available (Greenspan, 1979, 1981). It should also be pointed out that through videotaped analyses of infant-caregiver interactions (Creenspan and Lieberman, 1981; Hofheimer, et al., 1983) these patterns can be reliably rated and new raters trained to and kept at high levels of reliability.

Three, a special challenge; infants of the multi-risk family and developmental morbidity. My colleagues and I in the Clinical Infant Research Unit at the Mental Health Study Center of the National Institute of Mental Health in Adelphi, Maryland, have been able to obtain an indepth picture of the unfolding of infant morbidity particularly psychological, social and cognitive malfunction in the multiple-risk factor family. Families were referred because of severe interferences with their capacity to provide primary and secondary maternal functions for their children as indicated by demonstrated difficulty in rearing an older child who was manifesting severe psychological, social, and cognitive problems.

We use the term "multiple risk factor families" for those not only at risk of infant mortality and perinatal morbidity, but also for those in which the children appear to be at risk of "developmental morbidity." Our clinical impression is that families at the high-risk end of the spectrum in respect to any single risk factor, for example, substance abuse or poor nutrition, often evidence multirisk factors. Such families have also been described as "multiproblem," "hard to reach," "crisis-oriented," and so forth—Pavenstedt, 1967; Buell, 1952; Curtis, et al., 1964; Geismar and Sorte, 1964; Minuchin and Montalvo, 1967; Minuchin et al., 1967; Riessman, 1964; Riessman et al., 1964; Zilbach, 1971.

In addition, they have been classified by the way they use the service system and according to the kinds and numbers of problems they have. Results of the latter approach suggest that poverty or welfare status is not the only identifying characteristics, since families across the socieconomic strata evidence the same multi-problem characteristics [Mazer, 1972].

In spite of definitional differences, there has been general consensus on the clinical characteristics of these families. They tend, for example, to think only in concrete terms, to be need-oriented, and to have difficulty in anticipating the future and conceptualizing the consequences of their actions.

The parents operate on a survival basis, often competing with their children for concrete, as well as psychological and social, supports [Pavenstedt, 1967; Minuchin and Montalvo, 1967; Zilbach, 1971; Geismar, 1968; LaVietes, 1974; Levine, 1964; McMahon, 1964]. Although most of the families share these characteristics, an individual family may differ in some respects. Some of the families evidence clearly diagnosable mental illness such as a psychosis, and some, a predominance of severe antisocial and asocial personality patterns.

Others are characterized by passivity and inadequacy in coping with life's daily challenges. Individual clusters of symptomatic behaviors also characterize the families—psychotic symptoms, child abuse, spouse abuse, marital difficulties, crime, delinquency, alcoholism, physical illness, and suicide [Pavenstedt, 1967; Buell, 1952; Geismar and La Sorte, 1964; Minuchin et al., 1967; Mazer, 1972].

While for the most part these families have been thought of as a social problem, careful psychiatric and psychosocial evaluations of our population revealed a high incidence of psychiatric disturbance and history of impaired psychosocial functioning.

Estimates vary regarding the use of health, social services, and welfare systems by these families. However, the significance of the challenge that they present is indicated by a study conducted some time ago in which 6 percent of the study population was found to be using 45 percent of all public health resources and 55 percent of all social, psychiatric, and other auxillary services. It has been estimated that this 6 percent use approximately 70 percent of all public expenditures for health, social, and auxiliary services; a report of the congressionally authorized Joint Commission on the Mental Health of Children, 1965. While there are no similar recent data, a guess is that the problem may be much greater now.

Few indepth studies have been conducted of the development of the children in multirisk factor families. In the classic descriptive study of Pavenstedt of 1967, only 13 of such families, which had 40 to 50 children between the ages of 2½ and 6 years, were studied. Nevertheless, the clinical impressions from the study were striking. Almost all the children showed social and psychological characteristics more consistent with 1½- to 2-year-olds in their egocentricity and need orientation.

Their ability to use a symbolic or representational mode to plan for their own needs and to consider the needs and actions of others was limited, and they had variable self-esteem. They tended to think in fragmented, isolated units, rather than in cohesive patterns. They were not capable of goal-directed organized action and were limited in their ability to socialize and interact appropriately for their age. The children already had an ingrained defeatist attitude and the core of an aimless, either asocial or antisocial personality. The conclusion of the study was that there was a dire need to understand the developmenal process in such children from the prenatal stage into later childhood.

Subsequently, no indepth longitudinal studies have been done beginning with the prenatal period and following the children in multi-risk-factor families for 5 or more years, as is necessary to obtain information on how the behavioral patterns of these children develop and to gain insignt into the repetitive, multi-generational nature of these families' problems.

It seemed especially critical to identify the adaptive and maladaptive developmental patterns of such children and their families over time and to determine the clinical and service system techniques that are appropriate for preventive intervention. Therefore, we undertook a study of multi-risk-factor families. We provided periodic evaluations of the children in such families, based on standardized tests and naturalistic clinical and standardized recorded observations; for example, video tapes of interactions between the children and their care givers.

We have been able to study in depth for 2 or more years some 50 multi-risk factor families with more than 200 children. Efforts made to recruit these families and the clinical service approaches and assessments are described elsewhere.

It quickly became apparent to the staff in the program that we were dealing with families of various composition that were evidencing many risk factors such as psychiatric impairment, low educational and socioeconomic status, not only in the case of the parents who were the potential participants in our program, but also in the case of their own parents, high levels of social and psychological stress during the woman's pregnancy, and varying degrees of nutritional deficits and substance abuse.

It also became apparent that infant morbidity, infant mortality, and perinatal morbidity all may be related to the same common factors—incapacities of the infant's caregivers for self-care, care of another, planning around a pregnancy or a child's developmental processes. In our group of multi-risk-factor families, successful prenatal intervention reduced the expected levels of both infant mortality and immediate postnatal morbidity; few of the babies were born with physical or neurological handicaps. Yet we quickly observed that the next challenge, and in many respects the far more difficult one, was to reduce developmental morbidity.

I will discuss only some preliminary trends observed in children's development. These trends will be presented in a theoretical framework in which the stages of a child's early development and the adaptive infant and family patterns that can be expected in each phase of the child's development—as revealed in our work—are conceptualized. The trends described will not apply to every multi-risk factor family, since different families and different infants apparently experience arrest at various levels of development.

Intensive work with multi-risk-factor families, however, has shown us that they rarely are able to negotiate an infant's development into the second year of life without there being evidence of disruption in their infant's development and a need for specific services to overcome it. We have been able to identify the point at which the family fails to support the infant's development and at which the subsequent disordered development occurs.

We also have gained a preliminary impression of a distribution in which the more disturbed families show difficulties early in the infant's first year, whereas in some of the less disturbed families, there is no evidence of the likelihood of morbidity until the second year of life. In general, none of the multi-risk-factor families studies have been totally free of the morbidity described in this section.

We have observed babies in the program who during the first few days of life are, for the most part, well in terms of weight, size, and overall physical health status, but who have difficulty in regulating social responsiveness, establishing habituation patterns, and organizing their motor responses. Most of them are withdrawn and unresponsive to animate stimuli; others are hyperlabile and overly responsive. Nevertheless, in contrast, a number of our babies also seem to be in optimal condition, even in terms of the soft neurological signs, and are appropriately adaptive in their initial capacity for homeostasis—self-regulation and an emerging interest in the world.

Yet, in general, babies in our program, most of whom were at risk prenatally but who had normal patterns of development perinatally—prenatal intervention having assured adequate nutrition and other supports, including appropriate medical care—show significantly less than optimal development as early as the first month of life. Pediatric, neurological, and Brazelton neonatal examinations at 1 month of age, for example, show developmental progression but not the increased capacity for orientation characteristic of a normative population.

Interestingly, the group receiving comprehensive intervention was similar to normal comparison infants at birth but was slightly lower in their orientation capacity by 1 month. Our high-risk group, receiving only periodic evaluations, tended to be worse in a number of areas, including orientation, habituation, and motor organization—even with some of the most disturbed families having left the program; that is, those with the greatest risk—than both the normal and intervention groups at 1 month. By 3 months of age, instead of a capacity for self-regulation, organization, and an interest in the world, a number of our babies show increased tendencies toward lability, muscle rigidity, gaze aversion, and an absence of organized sleep-wake, alert, and feeding patterns. Their caregivers, instead of having an overall capacity for offering the babies comfort, protection, and an interest in the world, either tend to withdraw from them and avoid them or overstimulate them in a chaotic and intermittent fashion.

At about the ages of 2 to 4 months, we expect to find in the infant the beginnings of a deep rich emotional investment in the human world, especially in his primary caregivers. We also expect a human environment that will fall in love with the child and will woo that child to fall in love in turn, in an effective, multimodal, pleasurable manner. Instead, a significant number of these children exhibit a total lack of involvement in the human world or an involvement that is nonaffective, shallow, and impersonal, and we see caregivers who are emotionally distant, aloof, impersonal, and highly ambivalent about their children.

Between 3 and 9 months of age, we expect an infant's capacity for interacting with the world in a reciprocal, causal, or purposeful manner to further develop and form a foundation for his later organized causal behavior or thinking—reality orientation and testing. Instead, in the multi-problem families, the child's behavior and affects remain under the control of his internal states in random and chaotic or narrow, rigid, and stereotyped patterns of interaction. The child's environment, instead of offering the expected optimal contingent responsiveness to the child's varied signals, tends to ignore or misread them. The child's caregivers are overly preoccupied, depressed, or chaotic.

Toward the end of the first year of life and the beginning of the second, a child in a multiple risk factor family, instead of showing an increase in organized, complex, assertive, and innovative emotional and behavioral patterns—for example, taking his mother's hand and leading her to the refrigerator to show her the kind of food he wants—tends to exhibit fragmented, stereotyped, and polarized patterns. These toddlers may be withdrawn and compliant or highly aggressive, impulsive, and disorganized. Their human environment tends to be intrusive, controlling, and fragmented. The toddler may have been prematurely separated from his caregivers or the caregivers may exhibit patterns of withdrawal instead of admiringly supporting the toddler's initiative and autonomy and helping him to organize what are now more complex capacities for communicating, interacting, and behaving.

As the toddler's potential capacities continue to develop in the latter half of the second year and in the third (18 to 36 months), profound deficits can be more clearly observed. The child, instead of developing capacities for internal representations—imagery—around which to organize his behavior and feelings and for differentiating ideas, feelings, and thoughts pertaining to the self and the nonself, either develops no representational or symbolic capacity, or if the capacity develops, it is not elaborated beyond the most elementary descriptive form so that the child's behavior remains shallow and polarized.

His sense of the emerging self, as distinguished from the sense of other people, remains fragmented and undifferentiated. The child's potentially emerging capacities for reality testing, impulse regulation, and mood stabilization are either compromised or become extremely vulnerable to regression. In other words, we see patterns either consistent with later border line and psychotic personality organization or severe asocial or antisocial impulse-ridden character disorders.

At this stage, the underlying impairment manifests itself in the child's inability to use a representational or symbolic mode to organize his behavior. In essence, the distinctly human capacity of operating beyond the survival level, of using internal imagery to elaborate and organize complex feelings and wishes and to construct trial actions in the emotional sphere, and of anticipating and planning ahead are compromised.

In many of our families, the parents simply do not have these capacities. Even when they are not under emotional distress or in States of crisis or panic, they do not demonstrate a symbolic mode, as evidenced in the lack of verbal communication—only one aspect of symbolic communication—and in the lack of symbolic play. Such families tend to be fearful and to deny and fail to meet needs in their children that are appropriate for their ages. They engage the child only in nonsymbolic modes of communication, such as holding, feeding, and administering physical punishment, and at times they misread or respond unrealistically to the child's emerging communication, thus undermining the development in the child of a sense of self and a flexible orientation to reality.

Needless to say, the mastery by the children in these families of higher level developmental tasks is even more difficulty. At each new level of development, the infants and toddlers who for a variety of reasons have survived earlier developmental phases intact invariably challenge the multi-risk-factor environment with their new capacities, for example, with their capacity for symbolic communication. The healthier the toddler, the more challenging and overwhelming he is likely to be to the people around him.

Developmental Basis for Psychopathology and Adaptation in Infancy and Early Childhood [1]

Stage-specific tasks and capacities	Capacities		Environment (caregiver)	
	Adaptive	Maladaptive (pathologist)	Adaptive	Maladaptive
Homeostasis (0–3 mo) (self regulation and interest in the world.).	Internal regulation (harmony) and balanced interest in world.	Unregulated (e.g., hyperexcitable), withdrawn (apathetic).	Invested, dedicated, protective, comforting, predictable, engaging interesting.	Unavailable, chaotic, dangerous, abusive; hypostimulating or hyperstimulating; dull.
Attachment (2–7 mo)	Rich, deep, multisensory emotional investment in animate world (especially with primary caregivers).	Total lack of, or nonaffective, shallow, impersonal, involvement (e.g., autistic patterns) in animate world.	In love and woos infant to "fall in love"; affective multimodality pleasurable involvement.	Emotionally distant, aloof, and/or impersonal (highly ambivalent).
Somatopsychologic differentiation (3–10 mo) (purposeful, "cause and effect" signaling or communication).	Flexible, wide-ranging affective multisystem contingent (reciprocal) interactions (especially with primary caregivers).	Behavior and affects random and or chaotic, or narrow, rigid, and stereotyped.	Reads and responds contingently to infant's communications across multiple sensory and affective systems.	Ignores infant's communications (e.g., overly intrusive, preoccupied, or depressed) or misreads infant's communication (e.g., projection).
Behavioral organization, initiative, and internalization (99–24 mo).	Complex, organized, assertive, innovative, integrated behavioral and emotional patterns.	Fragmented, stereotyped, and polarized behavior and emotions (e.g., withdrawn, compliant, hyperaggressive, or disorganized toddlers).	Admiring of toddler's initiative and autonomy, yet available, tolerant, and firm; follows toddler's lead and helps him organize diverse behavioral and affective elements.	Overly intrusive, controlling; fragmented, fearful (especially of toddler's autonomy); abruptly and prematurely "separates".
Representational capacity, differentiation, and consolidation (1½–4 yr) (the use of ideas to guide language pretend play and behavior and eventually thinking and planning).	Formation and elaboration of internal representations (imagery). Organization and differentiation of imagery pertaining to self and nonself; emergence of cognitive insight. Stabilization of mood and gradual emergency of basic personality functions.	No representational (symbolic) elaboration; behavior and affect concrete, shallow, and polarize; sense of self and other fragmented and undifferentiated or narrow and rigid; reality testing, impulse regulations, mood stabilization compromised or vulnerable (e.g., borderline psychotic and severe character problems).	Emotionally available to phase-appropriate regressions and dependency needs; reads, responds to, and encourages symbolic elaboration across emotional behavioral domains (e.g., love, pleasure, assertion) while fostering gradual reality orientation and internalization of limits.	Fearful of or denies phase-appropriate needs; engages child only in concrete (nonsymbolic) modes generally or in certain realms (e.g., around pleasure) and or misreads or responds noncontingently or nonrealistically to emerging communications (i.e., undermines reality orientation); overly permissive or punitive.
Capacity for limited extended representational systems and multiple extended representational systems (middle childhood through adolescence).	Enhanced and eventually optimal flexibility to conserve and transform complex and organized representations of experience in the context of expanded relationship patterns and phase-expected developmental tasks.	Derivative representational capacities limited or defective, as are latency and adolescent relationships and coping capacities.	Supports complex, phase- and age-appropriate experiential and interpersonal development (i.e., into triangular and posttriangular patterns).	Conflicted over child's age-appropriate propensities (e.g., competitiveness, pleasure orientation growing competence, assertiveness, and self-sufficiency); becomes aloof or maintains symbolic tie; withdraws from or overengages in competitive or pleasurable strivings.

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[1] Chart appears in: Greenspan, Stanley I., "Psychopathology and Adaptation in Infancy and Early Childhood; Principles of Clinical Diagnosis and Preventive Intervention," Clinical Infant Reports, No. 1. New York. International Universities Press, 1981. Greenspan, S. I. & Greenspan, N. T., The Emotional Care of the Infant and Young Child. In press, McGraw Hill, to be published in 1983.

In a pattern that we have frequently observed, the child moves ahead of the parent, engaging, for example, in symbolic play around themes of dependency or sexuality, and thus the parent becomes confused and either withdraws from or behaves intrusively toward the child. Shortly, unless other more skillful caregivers are available, the child begins to regress to presymbolic modes of behaving. The child may be able to consolidate his higher level capacities when he begins to receive support from other systems, such as the school, and is capable of understanding his parents' limitations.

These capacities, however, can only develop when the child is a little older. The youngster who experiences developmental failures, including the failure to develop a full representational or symbolic capacity—the basis for formal school experience later on—will unquestionably be handicapped in all subsequent opportunities for learning.

Response to preventive clinical and service system approaches; the potential for recovery: On the encouraging side, we have found that in most of the families we work with, the maladaptive trends just described can be reversed. By carefully pinpointing the area in which a child's development first begins to go awry and by using organized and comprehensive clinical techniques and service system approaches, we have been able to effect significant reversals in the direction of more adaptive patterns.

Many parents in our population began their childrearing as teenagers and have commonly experienced further deterioration in their own functioning and that of their infants with each subsequent birth. In most instances, however, even when a woman has had four or more children, we have been able to reverse this pattern of deterioration by means of appropriate clinical methods and services.

In a number of these multi-risk-factor families, we have observed that after they enter our program, a gradual improvement takes place in the mother and a modest but positive change in the first baby born thereafter. Then, if the family remains in the program and a second baby is born, the change in the family is dramatic and is reflected in the new baby's more optimal development.

For example, Mrs. E was pregnant when she came to our attention. At first glance, she appeared to the team social worker to be beyond help after she was found sleeping on the street. All of her children had been removed from her care by the County Department of Protective Services after she had severely abused and neglected them. Mrs. E appeared unable to think except in concrete terms, at times was psychotic, could not communicate her thoughts and plans, and seemingly lived by impulse only and a talent for survival.

Shortly before the birth of her child a few months later, however, she entered our program, prompted by our outreach efforts. All of our collective efforts to induce Mrs. E to use a support structure—for example, to obtain housing, food or clothing—failed. Nevertheless, subsequently, of her own accord, she requested foster care for the new infant before severe trauma could be inflicted on the child.

Mrs. E maintained contact with this child and made a great deal of progress in treatment over a 2-year period. When she became pregnant again, not only could she care for the newest baby but was able to work and support an apartment. Thus far, with therapeutic support, she has nurtured a competent 11-month-old and also has become constructively involved with her older children.

Even when improvement was not so dramatic, the expected patterns of deterioration often did not take place in our families, and some of them became capable of adequately supporting the growth and development of their children. Many mothers, for example, who previously had children taken away and put in foster care, became able to care for a new infant as well as for their older children. Also, some mothers who had been recurrently hospitalized for psychiatric illness in the past developed the ability to function appropriately with a new baby and have not been rehospitalized for psychiatric illness for two or more years.

We found that the babies in our families had a surprising capacity to recover from early developmental deviations. Even when an infant's development had deteriorated during the first 3 months of life—as evidenced by gaze aversion, muscle rigidity, and a state of liability—intervention with appropriate patterns of care, including special clinical techniques, could lead to adaptive homeostatic and attachment capacities within 1 to 2 months.

Infants would become apathetic and withdrawn and begin to show delays in sensorimotor development when no one would read their signals or respond to them. However, with patient, clinically informed care, they would begin interacting with people and, within 2 to 3 weeks of intensive intervention, would begin to catch up developmentally.

I can discuss only briefly some of the principles on which a clinical and service system approach to both multi-risk-factor and less at-risk families should be based. Services for the multi-risk families have been the subject of only limited study. I will try to present some perspective on the organization and service challenges for the child and family related to the child at each stage of his development.

A comprehensive approach, as indicated earlier, requires that a number of elements be combined: (a) Services that respond to concrete needs for survival—food, housing and so forth; (b) a planned effort to meet the need of the family and the child for an ongoing, trusting human relationship; (c) specific clinical techniques and services that focus on the many lines of a child's development and that are specific to the child's tasks at each developmental subphase; and (d) a special support structure to provide at one site partial or full therapeutic day care for the child, innovative outreach to the family, and ongoing training and supervision of the program staff.

To respond to the family's concrete needs, various community agencies need to be organized to build a foundation for the family's survival. However, this approach alone will not insure a family's survival, since many of the families, for a variety of reasons, are adept at circumventing offers of traditional supports.

The second component of a comprehensive effort, and one that is absolutely necessary for these families, is a human relationship with one or more workers. Such a relationship, however, is not easy to establish, because distrust is often ingrained in each parent as well as in the family as a unit. This human relationship needs to grow in ways paralleling the infant's development and needs to help the parents facilitate that development. To provide his human relationship, we have used both a team and a single primary clinician.

Organizing to respond to a family's concrete needs and offering the family a human relationship, however, are not enough. That human relationship must be able to help the parents understand some of their maladaptive coping strategies and teach them how to deal with their own primary needs and those of their infant. In addition, special clinical techniques and patterns of care, to reverse maladaptive developmental patterns in the areas of affect and social interaction, sensorimotor development, and cognition must be available at the appropriate time.

Moreover, in our clinical experience, the intervention must occur over a sufficiently long period to allow the family's own strengths to take over and sustain it. We are speaking here then not of a crisis intervention approach over a few months, but an approach that will be available to the families for several years at a minimum. We have found that after working with many of these families for some 2 years, the mother's capacity to nurture and facilitate the development of a new baby is significantly more advanced than when she entered the program pregnant with an earlier child.

Our impression is, when the helping relationship is offered over a period of time, the frequently observed trend of multi-problem families to deteriorate further upon the birth of each subsequent baby—a trend that often starts when the parents are still teenagers—begins to be reversed.

In addition, the approach to the multiple needs of these infants and their families must be integrated. Simply offering nutritional advice or educational counseling, providing cognitive stimulation, or taking an entirely infant-centered or entirely family-centered approach may not be sufficient. The infants have individual differences that dictate special patterns of care; at the same time, the concerns of their care givers and other family members have to be addressed. Each stage in the infant's and the family's development requires specialized clinical services and service system approaches.

Although the costs of offering programs of intervention are great, the costs of not offering them are even greater. The estimated six percent of the U.S. population that use 50 to 75 percent of all health, mental health, and social services account for economic and social costs that are compounded by the additional loss to society that these people might have contributed to the labor force and to other creative endeavors.

Programs of prevention are expensive, but they are not so costly as might be imagined, since even when services are offered to an entire high-risk community, only a small percentage of the families in that community will actually need the most intensive help.

Selma Fraiberg, as director of a Michigan infant mental health program, found that in a program offering a range of preventive services, including intensive individual clinical services, the average cost per family participating was $850. In terms of providing screening and backup for an entire community, the cost per family for such preventive services would average out to a significantly lesser amount.

Perhaps we need to look at the cost-benefit ratio. Using cases from our own study, we developed a model to project the probabilities—based on observed family patterns and clinical assumptions—of different outcomes with and without preventive intervention. While all projections, as with economic forecasting, are based on assumptions which may or may not be true, the trends we found are of interest. Also this model can be used with other assumptions. Projected benefits outweighed costs by five or six to one, depending on the degree of risk. Interestingly, in the cases at greater risk, in which initial costs might be high, the benefit to cost ratio was often better than in less severe cases, because the benefits of preventive intervention were relatively greater.

Four, implications for a prevention policy. These same principles also apply to less at-risk families. When it has been estimated by the Department of Education that 13 percent of our school age children require special services, and informally clinicians and teachers estimate another 15 percent from all social and economic backgrounds could easily benefit from special educational, health and mental health services, the challenge becomes clear.

Too many children from varying social and economic background are evidencing compromises in basic personality functions such as impulse control, self-esteem maintenance, capacity to concentrate, to relate warmly to others and even to test reality by the time they reach school. Equal opportunity is not possible for these children as they begin with handicaps, many of which we believe are preventable. Our concepts of education and health care must begin at the beginning when the nervous system is growing most rapidly. It grows to two-thirds its adult size in the first 3 years of life.

A family's "right" to programs that will help them identify lags in their infants' emotional, social, cognitive and neuromotor aspects of development must become a "given" as is the right to education later on. Not all families require the level of effort described earlier. Many families only require help in identifying lags and guidance in providing "special patterns of care" to help their infants function more competently. Other families require the four levels of preventive services described earlier. We must address both needs.

Thank you.

[Prepared statement of Dr. Stanley Greenspan follows:]

Prepared Statement of Stanley I. Greenspan, M.D., Chief, Clinical Infant Research Unit, Laboratory of Psychology and Psychopathology, Intramural Research Program, NIMH

It is an honor to be here and to have an opportunity to discuss the prevention of health and mental health problems in infants, young children and their families. First, I would like to thank The Honorable George Miller, Chairman; Dan Marriot, Ranking Minority Member; and William Lehman, Chairman of this Task Force on Prevention Strategies, for focusing the Country's attention on children, youth, and families and on prevention as one of three priority areas.

I am a Child Psychiatrist and Chief of the Clinical Infant Research Unit, Intramural Research Program, National Institute of Mental Health, DHHS. A major area of my professional interest is the adaptive and maladaptive emotional development of infants, children and their families. The following will reflect my own views as a clinician and researcher.

The main points I wish to emphasize are:

1. We know a great deal about normal emotional and intellectual development in infants and young children, probably more than any other phase of the life cycle, including adulthood. An enormous body of research documents the newborn's capacities to, among other things, use his senses for perceiving his environment, making visual and auditory discriminations, responding favorably to pleasure, emotional warmth and security, and responding unfavorably to deprivation of emotional and/or sensory experience or to erratic overstimulation which overwhelms his or her early integrative capacities. The healthy infant continually increases his capacity to process information and enter into ever more complex emotional, social and cognitive patterns during the early years.

2. Beginning with the first few months of life, we can now chart the emotional, social and cognitive milestones, much as we do the neuro-motor milestones of sitting, crawling, walking and talking. We can also chart disturbances or departures from these expected developmental patterns, and identify some of the constitutional and environmental factors associated with these disturbances. For example, during the first two months healthy infants increasingly have moments of a calm, but alert state where they practice using their senses of vision, hearing, smell and motion. In contrast, hyperexcitable infants have rigid muscles, arch their backs, look away rather than toward their caregivers, and over-react to normal touch or sounds. The hypo-reactive infants seem to "shut down" and evidence poor muscle tone; they do not alert or brighten to a variety of sensory and social overtures.

Some infants appear to begin life with maladaptive patterns. In such instances, even competent families may need guidance to figure out how to find just the right pattern of rocking, vocalizations and stroking to help their infants be calm, alert and interested in the sights and sounds of the world. Other infants start out able to evidence calm, alert, attentive states and appear to lose these early adaptive capacities. In these situations clinically we have observed either unavailable or overly intrusive, chaotic caregiving patterns. Regardless of whether the basis for the early maladaptive patterns appears to be constitutional or a result of early experiences, on a case-by-case basis, we observed that providing special patterns of care helped the infants return to competent developmental patterns.

By 2-4 months we can observe infants who evidence that enraptured emotional engagement where they seem fascinated with the human world. In response to their caregiver's smiling, talking face, they smile back, listen, and even move their arms in synchrony to their caregiver's voice. The infant's pleasurable emotions and the strong investment of the caregiver appear to motivate the infant to use and organize his senses and his sensory motor organization. In contrast we also observe infants who are already unresponsive to the human world, evidencing flat or despondent emotional expressions. They may look away rather than toward their caregivers and respond to the human voice with panic rather than comfort. Secondary sensory motor delays and severe communication problems are not uncommon. Here too, we have worked with cases where there were constitutional vulnerabilities, and others where the main problems were in the caregiving pattern and still others where both factors were present. Most encouragingly, special patterns of care tended to reverse the maladaptive behavior. It would appear that the infant has great plasiticity and recovery power if we provide him or her the opportunity for favorable development.

As the infant progresses, we can observe infants who learn cause and effect interactions (i.e., the world is lawful), and complex motor and social skills. Eventually by 18 months to 2 years they learn to use ideas to guide language, motility, imagination and eventually to think and plan. In contrast, we observe infants whose behavior remains random and chaotic, who never develop functional complex social patterns and the functional use of ideas. They eventually evidence language delays and deficits in thinking, imagination and such basic personality functions as knowing what is real from pretend, controlling impulses and mood, and focusing attention to concentrate and learn. We have been impressed by how important the second year of life is for the development of higher level emotional and conceptual skills. Many toddlers develop competently and are even precocious motorically until 15-16 months of age. However, we feel that because of a lack of appropriate experiences, they do not fully make the next step of using ideas to label and interpret feelings, to think, plan and learn new conceptual skills that are essential for school and eventual participation in an increasingly technological society. Special programs at this age may have enormous payoff for many of these children.

3. Most importantly, there is now a great deal of evidence from case studies and some emerging evidence from larger group studies that early identification and pre-

ventively oriented interventions can effectively reverse early maladaptive patterns and promote healthy development.

The elements we feel an intervention program must contain are:

A. A focus on the interactions of the multiple aspects of development, including physical-neurological, cognitive, emotional, social and familial. Offering preventive intervention to the infant and not the family or for intellectual lags and not emotional and social limitations ignores the complexity of human beings and their families.

B. Preventive intervention approaches tailored to the individual differences in infants, young children and their families.

C. The integration of three levels into the preventive intervention approaches: 1. Attention to concrete needs for survival, food, housing, care; 2. An ongoing human relationship with a key member of the intervention team; and 3. Availability of specialized clinical, diagnostic and preventive intervention approaches for complex problems such as infants with sensory hypersensitivities to touch or sound or parents with depressive illness or other disturbances.

4. There are especially challenging families referred to as multi-problem and more recently by our research group as multi-risk. Over 30 years ago it was estimated that they constituted 5 percent to 10 percent of the population but used 50 percent to 75 percent of all the public health, mental health and social services. No recent data on this population exist. One can only guess that this pattern may be even more extreme now.

In case studies, the children in these families were observed to have severe problems in such basic personality functions essential for school and later work and family life, as knowing the real from the pretend, controlling impulses and mood, and focusing attention and concentration in order to learn and interact with others. We have found that many of the emotional and cognitive disturbances of these children can be identified as early as the first months of life. Even families with more than three generations of marginal coping and a history of distrust of traditional services can be involved in an ongoing preventive intervention program. More importantly, on a case-by-case basis, we have been able to show that the at-risk infants, young children and their families can be helped to competent functioning.

The intergenerational nature of these patterns are important. Often the multi-risk mothers begin their child rearing as teenagers and they and their children do worse with each subsequent pregnancy. These mothers describe a similar pattern with their own mothers. And in all likelihood, their children will continue these patterns. We have observed in our cases that by helping a mother and family with one child, not only does that child and the whole family do better, but the next child does better. It appears that a negative cycle of geometric proportions is broken and a positive one begun.

5. The implications for a National health, mental health, and educational prevention policy should also be considered. With 13 percent of our school-age children receiving special services and, as a clinical hunch, another 15 percent who could probably benefit from such services, we must rethink our basic philosophy on such fundamental notions as equal opportunity and an education for all our children. When children enter school already handicaped in cognitive or emotional functioning, they do not have an equal opportunity. In addition, they have critical educational lags. Education, health and mental health care must begin at the "beginning," when the brain is growing most rapidly. The brain grows to two thirds of its adult size by the time a child is three. In my view, infants require phase specific nutriments of a biological (i.e, nutrition) and experimental (i.e., emotional, physical and cognitive experiences) nature geared to their own individual differences and stage specific requirements. While some infants have unusual capacities to find the "nutriments," if they are literally anywhere nearby, the "nutriments" must still be in the vicinity in some form or another. Having availability to the "nutriments" is essential for the attainment of critical milestones in the education, health and mental health of our infants in the first three years of life. These milestones include, as discussed earlier, learning to: 1) regulate one's body and use one's senses to perceive the world; 2) form distinctly human emotional relationships; 3) interact in a cause and effect or purposeful manner; 4) organize complex cognitive and emotional patterns; 5) construct ideas to guide language, behavior and feelings; and 6) to think and plan. All these milestones which occur before children have access to school are critical to their health, mental health and education.

PART II

The following sections will briefly amplify each of the above points.

1. *Normal emotional and social development in infancy.*—While there are no larger scale studies of infants and young children's affective patterns at different ages to partition the range of emotional patterns in the general population, there is extensive literature on the emotional development of presumed normal infants. Interestingly, during the past fifteen years there has been considerably greater documentation of normal emotional development in infants than probably any other age group.

It is now well-documented that the infant is capable, even at birth and/or shortly thereafter, of organizing experience in an adaptive fashion. He or she can respond to pleasure and displeasure (Lipsett, 1966); change behavior as a function of its consequences (Gewirtz, 1965, 1969); form intimate bonds and make visual discriminations (Klaus and Kennell, 1976; Meltzoff and Moore, 1977); organize cycles and rhythms, e.g., sleep-awake, alertness states (Sander, 1962); evidence a variety of affects or affect proclivities (Tomkins, 1981; Izard, 1978; and Ekman, 1972); and demonstrate organized social responses in conjunction with increasing neurophysiologic organization (Emde, Gaensbauer and Harmon, 1976) (the infant from the early months demonstrates a unique capacity to enter into complex social and affective interactions (Stern, 1974a, 1974b, 1977; Brazelton, 1974). It is interesting to note that this empirically documented view of the infant is, in a general sense, consistent with Freud's early hypotheses (1911) and Hartmann's postulation (1939) of an early undifferentiated organization matrix. That the organization of experience broadens during the early months of life to reflect increases in the capacity to experience and tolerate a range of stimuli, including responding in social interaction in stable and personal configurations, is also consistent with recent empirical data (Emde et al., 1976; Sroufe, Waters and Matas, 1974; Escalona, 1968; Stern, 1974a, 1974b; Sander, 1962; Brazelton, Koslowski and Main, 1974; Murphy and Moriarty, 1976). That increasingly complex patterns continue to emerge as the infant further develops is indicated by complex emotional responses such as surprise (Charlesworth, 1969) and affiliation, wariness and fear (Ainsworth, Bell and Stayton, 1974; Bowlby, 1969; Sroufe and Waters, 1977), observed between 7 and 12 months; exploration and "refueling" patterns (Mahler, Pine and Bergman, 1975); behavior suggesting functional understanding of objects (Werner and Kaplan, 1963) observed in the middle to latter part of the second year of life and the eventual emergence of symbolic capacities (Piaget, 1962; Gouin-Decarie, 1965; Bell, 1970).

In the above studies, there is a consensus (and there are no dissenting studies) that by two to four months of age at the latest, and often much earlier, healthy infants are capable of responding to their caregivers' faces, smiles, and voices with brightening or alerting and, often, with a smile and reciprocal vocalizations (suggesting positive affect) as well as other reciprocal responses. Furthermore, infant-caregiver's interaction patterns become progressive characterized by more complex social interaction as development proceeds.

2. *Comparison of adaptive (normal) and maladaptive developmental patterns in infancy*—A. Psychopathology in infancy: The study of psychopathology in infancy is a new area even though the historical foundation for identifying disturbances in the early years of life is very impressive. Constitutional and maturational patterns which influenced the formation of early relationship patterns were already noted in the early 1900's with descriptions of "babies of nervous inheritance" who exhaust their mothers (Cameron, 1919) and infants with "excessive nerve activity and a functionally immature" nervous system.

Winnicott, who as a pediatrician in the 1930's began describing the environment's role in early relationship problems (1931), was followed in the 1940's by the well known studies describing the severe developmental disturbances of infants brought up in institutions or in other situations of emotional deprivation (Lowrey, 1940; Hunt, 1941; Bakwin, 1942; Bowlby, 1952; Spitz, 1945). Spitz's films resulted in laws in the United States prohibiting care of infants in institutions.

The role of individual differences in the infant based on constitutional maturational and early interactional patterns (i.e., "nervous" infants described by Cameron 1919 and Ford 1905 in the early 1900's) again became a focus of inquiry, as evidenced by the observations of Burlingham and A. Freud (1942); Bergman and Escalona's descriptions of infants with "unusual sensitivities" (1949); Escalona, Heide, Moriarity and Murphy's overview (1976); Murphy's vulnerability index (1976); Chess and Thomas' temperament studies (1977); Cravioto and DeLicardie's descriptions of the role of infant individual differences in malnutrition; and the impressive emerging empirical literature on infants (Sander, 1962; Brazelton, 1974; Lipsett, 1966; Stern, 1974; Emde, 1976; Gewirtz, 1961; and Reingold, 1961, 1963. More integrated approaches to understanding disturbances in infancy has been emphasized in descriptions of selected disorders and very insightful clinical case studies (e.g., Fraiberg, 1970; Provence, 1979, in press; Williams, et al., in press).

In order to foster preventive efforts, we at the Clinical Infant Research Unit, Intramural Research Program, National Institute of Mental health, undertook a study of normal and disturbed developmental patterns in infancy in order to develop a more comprehensive classification of adaptive and maladaptive infant and family patterns. Below is a chart summarizing the adaptive and malaptive infant and family patterns followed by a brief description of these patterns (see Greenspan, 1979; Greenspan, Lourie and Nover, 1979; Grennspan and Lourie, 1981; Greenspan, 1981 for a more detailed description of these patterns).

The capacities described by these stages are all present in some rudimentary form in very early infancy. The sequence presented suggests not when these capacities begin, but when they become relatively prominent in organizing behavior and furthering development. In this classification the first stage is the achievement of homeostasis, i.e., self regulation and emerging interest through the senses in the world—sights, sounds, smells, touch, etc. Once the infant has achieved some capacity for regulation in the context of engaging the world, and central nervous system (CNS) maturation is increasing (between 2 and 4 months of age), he becomes more attuned to social and interpersonal interaction. He is more able to respond to the external environment and to form a special relationship with the significant primary caregivers. Thus, a second, closely related stage is that of forming a human attachment. If an affective and relatively pleasurable attachment (an investment in the human, animate world) is formed, then with growing maturational abilities, the infant develops complex patterns of communication in the context of this primary human relationship. Parallel with development of the infant's relationship to the inanimate world where basic schemes of causality (means/ends relationships Piaget, 1972) are being developed, the infant becomes capable of complicated human communications (Brazelton, et al., 1974; Stern, 1974a; Tennes, et al., 1972; Charlesworth, 1969).

When there have been distortions in the attachment process (e.g., if a mother responds in a mechanical, remote manner and/or projects some of her own dependent feelings onto her infant), the infant may not learn to appreciate causal relationships between people at the level of compassionate and intimate feelings. This can occur even though causality seems to be developing in terms of the inanimate world and the impersonal human world. We have observed infants who are differentiated in the assertive impersonal domain of human relationships but who are relatively undifferentiated in the intimate, pleasurable domain.

Causual relationships are established between the infant and the primary caregiver as evidenced in the infant's growing ability to discriminate significant primary caregivers from others. He also becomes able to differentiate his own actions from their consequences, affectively, somatically, behaviorally, and interpersonally. Usually by eight months of age or earlier, the process of differentiation begins along a number of developmental lines (e.g., with sensorimotor integration, affects, relationships). A third stage therefore may be formally termed somatopsychologic differentiation to indicate processes occurring at the somatic (e.g., sensorimotor) and emerging psychological levels. (In this context, psychologic refers to higher level mental processes characterized by the capacity to form internal representations or symbols as a way to organize experience.) While schemes of casuality are being established in the infant's relationship to the interpersonal world, it is not at all clear whether these schemes exist at an organized representational or symbolic level. Rather, they appear to exist mainly at a somatic level (Greenspan, 1979), even though we do observe the precursors of representational capacities. Some are perhaps even prenatally determined (Lourie, 1971).

With appropriate reading of cues and systematic differential responses, the infant's or toddler's behavioral repertoire becomes complicated and communications take on more organized, meaningful configurations. By 12 months of age, the infant is connecting behavioral units into larger organizations as he exhibits complex emotional responses such as affiliation, wariness, and fear (Bowlby, 1969; Ainsworth et al., 1974; Sroufe and Waters, 1977). As the toddler moves farther into the second year of life, in the context of the practicing subphase of the development of individuation (Mahler et al., 1975), there is an increased capacity for forming original behavioral schemes (Piaget, 1972) and imitative activity and intentionality.

A type of learning through imitation evidence in earlier development now seems to assume a more dominant role. As imitations take on a more integrated personal form, it appears the toddler is adopting or internalizing attributes of his caregivers. To describe these new capacities it is useful to consider a fourth stage, that of behavioral organization, initiative, and internalization.

As the toddler moves into the end of the second year, with further CNS maturation, we notice an increased capacity to form and organize mental representations (i.e., ideas). Internal sensations and unstable images become organized in a mental representational form which can be evoked and is somewhat stable (Piaget, 1972; Bell, 1970; Gouin-Decarie, 1965). While this capacity is initially fragile (i.e., between 16 and 24 months), it soon appears to become a dominant mode in organizing the child's behavior, and a fifth stage can be documented, that of forming mental representations or ideas. As a clarification of related concepts, it should be pointed out that the capacity for "object permanence" is relative and goes through a series of stages (Gouin-Decarie, 1965); it refers to the toddler's ability to search for hidden inanimate objects. Representational capacity refers to the ability to organize and evoke internal organized multisensory experiences of the animate object. The capacities to represent animate and inanimate experiences are related and depend both on CNS myelination and appropriate experiences. The process of "internalization" may be thought of as an intermediary process. Internalized experiences eventually becomes sufficiently organized to be considered representations.

At a representational level the child again develops his capacities for elaboration, integration, and differentiation. Just as causal schemes previously were developed at a somatic and behavioral level, now they are developed at a representational level. The child begins to elaborate and eventually differentiate those feelings, thoughts, and events that emanate from himself and those that emanate from others. He begins to differentiate what he experiences and does from the impact of his actions on the world. This gradually forms the basis for the differentiation of "self" representations from those which embody the external world, animate and inanimate, and also provides the basis for such crucial personality functions as knowing what is real from unreal, impulse and mood regulation, and the capacity to focus attention and concentrate in order to learn and interact.

The capacity for differentiating internal representations becomes consolidated as object constancy is established (Mahler et al., 1975). In middle childhood, representational capacity becomes reinforced, with the child's ability to develop derivative representational systems tied to the original representation and transforms them in accord with adaptive and defensive goals. This permits greater flexibility in dealing with perceptions, feelings, thoughts, and emerging ideals. Substages for these capacities include representational differentiation, the consolidation of representational capacity, and the capacity for forming limited derivative representational systems and multiple derivative representational systems (structural learning [Greenspan, 1979]).

At each of these stages in varying degrees, pathologic as well as adaptive formations are possible. These may be considered as relative compromises in the range, depth, stability, and/or personal uniqueness of the experiential organization consolidated at each stage. The infant can form adaptive patterns of regulation in the earliest stages of development. His internal states are harmoniously regulated and he is free to invest himself in the animate and inanimate world, thereby setting the basis for rich emotional attachments to his primary caregivers. On the other hand, if his regulatory processes are not functioning properly and he cannot maintain internal harmony in the context of being available to the world, the infant may withdraw. From relatively minor compromises such as a tendency to withdraw and/or be hyperexcitable under stress, to a major deviation such as an overwhelming avoidance of the animate world, we can observe the degree to which the infant, even in the first months of life, achieves a less-than optimal adaptive structural organization.

Thus, the early attachments can be warm and engaging, or shallow, insecure, and limited in their affective tone. In the early reciprocal relationships, we can observe differences between an infant who reads the signals of the caregivers and responds in a rich, meaningful way to multiple aspects of the communications (with multiple affects and behavioral communications), and one who can respond only within a narrow range of affect (e.g., protest) or who cannot respond at all in a contigent or reciprocal manner (e.g., the seemingly apathetic, withdrawn, and depressed child who responds only to his own internal cues). As the toddler, optimally, becomes behaviorally more organized and complex patterns appear which reflect originality and initiative in the context of the separation and individuation subphase of development, we can observe those toddlers who manifest this full adaptive capacity. They may be compared with others who are stereotyped in their behavioral patterns (reflect no originality or intentionality), who remain fragmented (never connect pieces of behavior into more complicated patterns), or who evidence polarities of affect, showing no capacity to integrate emotions (e.g., the chronic negativistic aggressive toddler who cannot show interest, curiosity, or love).

As a capacity for representational organization is reached, we can distinguish the child who can organize, integrate, and differentiate a rich range of affective and ideational life from one who remains either without representational capacity or undifferentiated (i.e., deficits with reality testing, impulse control, focused concentration, or who may form and differentiate self and object representations only at the expense of extreme compromises in the range of tolerated experience (e.g., the schizoid child who withdraws from relationships). Similar adaptive or maladaptive structural organizations can be observed in later childhood (the triangular phase), latency, and adolescence.

A more detailed discussion of this framework, including principles of prevention and intervention, is available (Greenspan, 1979, 1981). It should also be pointed out that through videotaped analyses of infant-caregiver interactions (Greenspan and Lieberman, 1981; Hofheimer, et al., 1983) these patterns can be reliably rated and new raters trained to and kept at high levels of reliability.

3. *A special challenge; infants of the multi-risk family and developmental morbidity.*—My colleagues and I in the Clinical Infant Research Unit at the Mental Health Study Center of the National Institute of Mental Health in Adelphi, Md., have been able to obtain an indepth picture of the unfolding of infant morbidity particularly psychological, social, and cognitive malfunction in the multiple-risk-factor family. Families were referred because of severe interferences with their capacity to provide primary and secondary maternal functions for their children as indicated by demonstrated difficulty in rearing an older child who was manifesting severe psychological, social, and cognitive problems.

We use the term "multiple-risk-factor families" for those not only at risk of infant mortality and perinatal morbidity, but also for those in which the children appear to be at risk of "developmental morbidity." Our clinicial impression is that families at the high-risk end of the spectrum in respect to any single risk factor, for example, substance abuse or poor nutrition, often evidence multi-risk factors. Such families have also been described as "multi-problem," "hard-to-reach," "crisis-oriented," and so forth (Pavenstedt, 1967; Buell, 1952; Curtis et al., 1964; Geismar and Sorte, 1964; Minuchin and Montalvo, 1967; Minuchin et al., 1967; Riessman, 1964; Riesman et al., 1964; Zilbach, 1971). In addition, they have been classified by the way they use the service system and according to the kinds and number of problems they have. Results of the latter approach suggest that poverty or welfare status is not the only identifying characteristics, since families across the socioeconomic strata evidence the same multi-problem characteristics (Mazer, 1972).

In spite of definitional differences, there has been general consensus on the clinical characteristics of these families. They tend, for example, to think only in concrete terms, to be need-oriented, and to have difficulty in anticipating the future and conceptualizing the consequences of their actions. The parents operate on a survival basis, often competing with the children for concrete, as well as psychological and social, supports (Pavenstedt, 1967; Minuchin and Montalvo, 1967; Zilbach, 1971; Geismar, 1968; La Vietes, 1974; Levine, 1964; McMahon, 1964). Although most of the families share these characteristics, an individual family may differ in some respects. Some of the families evidence clearly diagnosable mental illness such as a psychosis, and some, a predominance of severe antisocial and asocial personality patterns. Others are characterized by passivity and inadequacy in coping with life's daily challenges. Individual clusters of symtomatic behaviors also characterize the families—psychotic symptoms, child abuse, spouse abuse, marital difficulties, crime, delinquency, alcoholism, physical illness, and suicide (Pavenstedt, 1967; Buell, 1952; Geismar and La Sorte, 1964; Minuchin et al., 1967; Mazer, 1972).

While for the most part, these families have been thought of as a social problem, careful psychiatric and psychosocial evaluations of our population revealed a high incidence of psychiatric disturbance and history of impaired psychosocial functioning (Jasnow et al., 1982).

Estimates vary regarding the use of health, social services, and welfare systems by these families. However, the significance of the challenge that they present is indicated by a study conducted some time ago (Buell, 1952), in which 6 percent of the study population was found to be using 45 percent of all public health resources and 55 percent of all social, psychiatric, and other auxiliary services. It has been estimated that this 6 percent use approximately 70 percent of all public expenditures for health, social, and auxiliary services (report of the congressionally authorized Joint Commission on the Mental Health of Children, 1965). While there are no similar recent data, a guess is that the problem may be much greater now.

CHILDREN IN MULTI-RISK-FACTOR FAMILIES

Few in-depth studies have been conducted of the development of the children in multi-risk-factor families. In the classic descriptive study of Pavenstedt (1967), only 13 of such familes (which had 40 to 50 children between the ages of 2½ and 6 years) were studied. Nevertheless, the clinical impressions from the study were striking. Almost all the children showed social and psychological characteristics more consistent with 1½ to 2-year-olds in their egocentricity and need-orientation. Their ability to use a symbolic (or representational) mode to plan for their own needs and to consider the needs and actions of others was limited, and they had variable self-esteem. They tended to think in fragmented, isolated units, rather than in cohesive patterns. They were not capable of goal-directed organized action and were limited in their ability to socialize and interact appropriately for their age. The children already had an ingrained defeatist attitude and the core of an aimless (either asocial or antisocial) personality. The conclusion of the study was that there was a dire need to understand the developmental process in such children from the prenatal stage into later childhood.

Subsequently, no indepth longitudinal studies have been done beginning with the prenatal period and following the children in multi-risk-factor families for 5 or more years, as is necessary to obtain information on how the behavioral patterns of these children develop and to gain insight into the repetitive, multi-generational nature of these families' problems. It seemed especially critical to identify the adaptive and maladaptive developmental patterns of such children and their families over time and to determine the clinical and service system techniques that are appropriate for preventive intervention. Therefore, we undertook a study of multi-risk factor families. We provided periodic evaluations of the children in such families, based on standardized tests and naturalistic clinical and standardized recorded observations (for example, videotapes of interactions between the children and their caregivers). We have been able to study in depth for two or more years some 50 multi-risk-factor families with more than 200 childern. Efforts made to recruit these families and the clinical service approaches and assessments are described elsewhere (Greenspan, 1981, Weider, et al., 1983; Greenspan, et al., 1983-in press).

It quickly became apparent to the staff in the program that we were dealing with families of various composition that were evidencing many risk factors such as psychiatric impairment, low educational and socioeconomic status (not only in the case of the parents who were the potential participants in our program, but also in the case of their own parents), high levels of social and psychological stress during the woman's pregnancy, and varying degrees of nutritional deficits and substance abuse.

It also became apparent that infant morbidity, infant mortality, and perinatal morbidity all may be related to the same common factors—incapacities of the infant's caregivers for self-care, care of another, planning around a pregnancy or a child's developmental processes. In our group of multi-risk-factor families, successful prenatal intervention reduced the expected levels of both infant mortality and immediate postnatal morbidity; few of the babies were born with physical or neurological handicaps. Yet we quickly observed that the next challenge, and in many respects the far more difficult one, was to reduce developmental morbidity.

PRELIMINARY REPORT ON OBSERVED TRENDS

I will discuss only some preliminary trends observed in children's development. These trends will be presented in a theoretical framework in which the stages of a child's early development and the adaptive infant and family patterns that can be expected in each phase of the child's development—as revealed in our work—are conceptualized. The trends described will not apply to every multi-risk-factor family, since different families and different infants apparently experience arrest at various levels of development. Intensive work with multi-risk-factor families, however, has shown us that they rarely are able to negotiate an infant's development into the second year of life without there being evidence of disruption in their infant's development and a need for specific services to overcome it. We have been able to identify the point at which the family fails to support the infant's development and at which the subsequent disordered development occurs. We also have gained a preliminary impression of a distribution in which the more disturbed families show difficulties early in the infant's first year, whereas in some of the less disturbed families, there is no evidence of the likelihood of morbidity until the second year of life. In general, none of the multi-risk-factor families studies have been totally free of the morbidity described in this section.

We have observed babies in the program who during the first few days of life are for the most part well in terms of weight, size, and overall physical health status, but who have difficulty in regulating social responsiveness, establishing habituation patterns, and organizing their motor responses. Some of them are withdrawn and unresponsive to animate stimuli; others are hyperlabile and overly responsive. Nevertheless, in contrast, a number of our babies also seem to be in optimal condition, even in terms of the soft neurological signs, and are appropriately adaptive in their intitial capacity for homeostasis (self-regulation and an emerging interest in the world).

Yet, in general, babies in our program, most of whom were at risk prenatally but who had normal patterns of development perinatally (prenatal intervention having assured adequate nutrition and other supports, including appropriate medical care), show significantly less than optimal development as early as the first month of life. Pediatric, neurological, and Brazelton neonatal examinations at one month of age, for example, show developmental progression but not the increased capacity for orientation characteristic of a normative population. Interestingly, the group receiving comprehensive intervention was similar to normal comparison infants at birth but was slightly lower in their orientation capacity by one month. One high-risk group, receiving only periodic evaluations, tended to be worse in a number of areas including orientation, habituation, and motor organization (even with some of the most disturbed families having left the program, i.e., those with the greatest risk) than both the normal and intervention groups at one month (Hofheimer et al., 1982).

By three months of age, instead of a capacity for self-regulation, organization, and an interest in the world, a number of our babies show increased tendencies toward lability, muscle rigidity, gaze aversion, and an absence of organized sleep-wake, alert, and feeding patterns. Their caregivers, instead of having an overall capacity for offering the babies comfort, protection, and an interest in the world, either tend to withdraw from them and avoid them or overstimulate them in a chaotic and intermittent fashion.

At about the ages of two to four months, we expect to find in the infant the beginnings of a deep rich emotional investment in the human world, expecially in his primary caregivers. We also expect a human environment that will "fall in love" with the child and will woo that child to fall in love in turn, in an effective, multimodal, pleasurable manner. Instead, a significant number of these children exhibit a total lack of involvement in the human world or an involvement that is nonaffective, shallow, and impersonal, and we see caregivers who are emotionally distant, aloof, impersonal, and highly ambivalent about their children.

Between three and nine months of age, we expect an infant's capacity for interacting with the world in a reciprocal, causal, or purposeful manner to further develop and form a foundation for his later organized causal behavior or thinking (reality orientation and testing). Instead, in the multi-problem families, the child's behavior and affects remain under the control of his internal states in random and chaotic or narrow, rigid, and stereotyped patterns or interaction. The child's environment, instead of offering the expected optimal contingent responsiveness to the child's varied signals, tends to ignore or misread them. The child's caregivers are overly preoccupied, depressed, or chaotic.

Toward the end of the first year of life and the beginning of the second, a child in a multiple-risk-factor family, instead of showing an increase in organized, complex, assertive, and innovative emotional and behavioral patterns (for example, taking his mother's hand and leading her to the refrigerator to show her the kind of food he wants), tends to exhibit fragmented, stereotyped, and polarized patterns. These toddlers may be withdrawn and compliant or highly aggressive, impulsive, and disorganized. Their human environment tends to be intrusive, controlling, and fragmented. The toddler may have been prematurely separated from his caregivers or the care-givers may exhibit patterns of withdrawal instead of admiringly supporting the toddlers initiative and autonomy and helping him to organize what are now more complex capacities for communicating, interacting, and behaving.

As the toddler's potential capacities continue to develop in the latter half of the second year and in the third (18-36 months), profound deficits can be more clearly observed. The child, instead of developing capacities for internal representations (imagery) around which to organize his behavior and feelings and for differentiating ideas, feelings, and thoughts pertaining to the self and the nonself, either develops no representational or symbolic capacity, or if the capacity develops, it is not elaborated beyond the most elementary descriptive form so that the child's behavior remains shallow and polarizes. His sense of the emerging self, as distinguished from the sense of other people, remains fragmented and undifferentiated. The child's potentially emerging capacities for reality testing, impulse regulation, and mood stabilization are either compromised or become extremely vulnerable to regression. In other words, we see patterns either consistent with later borderline and psychotic personality organization or severe asocial or antisocial impulse-ridden character disorders.

At this stage, the underlying impairment manifests itself in the child's inability to use a representational or symbolic mode to organize his behavior. In essence, the distinctly human capacity of operating beyond the survival level, of using internal imagery to elaborate and organize complex feelings and wishes and to construct trial actions in the emotional sphere, and of anticipating and planning ahead are compromised. In many of our families, the parents simply do not have these capacities. Even when they are not under emotional distress or in states of crisis or panic, they do not demonstrate a symbolic mode, as evidenced in the lack of verbal communication (only one aspect of symbolic communication) and in the lack of symbolic play. Such families tend to be fearful and to deny and fail to meet needs in their children that are appropriate for their ages. They engage the child only in nonsymbolic modes of communication, such as holding, feeding, and administering physical punishment, and at times they misread or respond unrealistically to the child's emerging communication, thus undermining the development in the child of a sense of self and a flexible orientation to reality.

Needless to say, the mastery by the children in these families of higher level developmental tasks is even more difficult. At each new level of development, the infants and toddlers who for a variety of reasons have survived earlier developmental phases intact invariably challenge the multi-risk-factor environment with their new capacities, for example, with their capacity for symbolic communication. The healthier the toddler, the more challenging and overwhelming he is likely to be to the people around him. In a pattern that we have frequently observed, the child moves ahead of the parent (engaging, for example, in symbolic play around themes of dependency or sexuality), and thus the parent becomes confused and either withdraws from, or behaves intrusively, toward the child. Shortly, unless other more skillful caregivers are available, the child begins to regress to presymbolic modes of behaving. The child may be able to consolidate his higher level capacities when he begins to receive support from other systems, such as the school, and is capable of understanding his parents' limitations. These capacities, however, can only develop when the child is a little older. The youngster who experiences developmental failures, including the failure to develop a full representational or symbolic capacity (the basis for formal school experience later on), will unquestionably be handicapped in all subsequent opportunities for learning.

RESPONSE TO PREVENTIVE CLINICAL AND SERVICE SYSTEM APPROACHES; THE POTENTIAL FOR RECOVERY

On the encouraging side, we have found that in most of the families we work with, the maladaptive trends just described can be reversed. By carefully pinpointing the area in which a child's development first begins to go awry and by using organized and comprehensive clinical techniques and service system approaches, we have been able to effect significant reversals in the direction of more adaptive patterns. Many parents in our population began their child-rearing as teenagers and have commonly experienced further deterioration in their own functioning and that of their infants with each subsequent birth. In most instances, however, even when a woman has had four or more children, we have been able to reverse this pattern of deterioration by means of appropriate clinical methods and services. In a number of these multi-risk-factor families, we have observed that after they enter our program, a gradual improvement takes place in the mother, and a modest but positive change in the first baby born thereafter. Then, if the family remains in the program and a second baby is born, the change in the family is dramatic and is reflected in the new baby's more optimal development.

For example, Mrs. E. was pregnant when she came to our attention. At first glance she appeared to the team social worker to be beyond help after she was found sleeping on the street. All of her children had been removed from her care by the County Department of Protective Services after she had severely abused and neglected them. Mrs. E. appeared unable to think except in concrete terms, at times was psychotic, could not communicate her thoughts and plans, and seemingly lived by impulse only and a talent for survival. Shortly before the birth of her child a few months later, however, she entered our program, prompted by our outreach efforts. All of our collective efforts to induce Mrs. E. to use a support structure (for example, to obtain housing, food, or clothing) failed. Nevertheless, subsequently, of her own accord, she requested foster care for the new infant before severe trauma could be inflicted on the child. Mrs. E. maintained contact with this child and made a great deal of progress in treatment over a 2-year period. When she became pregnant again, not only could she care for the newest baby but was able to work and support an apartment. Thus, far, with therapeutic support, she has nurtured a competent 11-month-old and also has become constructively involved with her older children.

Even when improvement was not so dramatic, the expected patterns of deterioration often did not take place in our families, and some of them became capable of adequately supporting the growth and development of their children. Many mothers, for example, who previously had children taken away and put in foster care became able to care for a new infant as well as for their older children. Also, some mothers who had been recurrently hospitalized for psychiatric illness in the past developed the ability to function appropriately with a new baby and have not been rehospitalized for psychiatric illness for two or more years.

We found that the babies in our families had a surprising capacity to recover from early developmental deviations. Even when an infant's development had deteriorated during the first 3 months of life (as evidenced by gaze aversion, muscle rigidity, and a state of lability), intervention with appropriate patterns of care (including special clinical techniques) could lead to adaptive homeostatic and attachment capacities within 1 to 2 months. Infants would become apathetic and withdrawn and begin to show delays in sensorimotor development when no one would read their signals or respond to them. However, with patient, clinically informed care, they would begin interacting with people and, within 2 to 3 weeks of intensive intervention, would begin to catch up developmentally.

PRINCIPLES OF PREVENTIVE CLINICAL SERVICES

I can discuss only briefly some of the principles on which a clinical and service system approach to both multi-risk-factor and less at-risk families should be based. Services for the multi-risk families have been the subject of only limited study, (Buell, 1952; Minuchin and Montalvo, 1967; Zilbach, 1971; La Vietes, 1974; Levine, 1964; Argles and MacKenzie, 1970; Berstein, 1964; Edelstein, 1972; Fantl, 1958; Gunter and MacCorquodale, 1974; Lang, 1974; Powell and Monahan, 1969; Reid and Shyne, 1969; Sperebas, 1974; Suarez, 1974). I will try to present some perspective on the organization and service challenges for the child and family related to the child at each stage of his development.

A comprehensive approach, as indicated earlier, requires that a number of elements be combined: (a) services that respond to concrete needs for survival (food, housing, and so forth), (b) a planned effort to meet the need of the family and the child for an ongoing, trusting human relationship, (c) specific clinical techniques and services that focus on the many lines of a child's development and that are specific to the child's tasks at each developmental subphase, and (d) a special support structure to provide at one site partial or full therapeutic day care for the child, innovative outreach to the family, and ongoing training and supervision of the program staff.

To respond to the family's concrete needs, various community agencies need to be organized to build a foundation for the family's survival. However, this approach alone will not ensure a family's survival, since many of the families, for a variety of reasons, are adept at circumventing offers of traditional supports.

The second component of a comprehensive effort, and one that is absolutely necessary for these families, is a human relationship with one or more workers. Such a relationship, however, is not easy to establish, because distrust is often ingrained in each parent as well as in the family as a unit. This human relationship needs to grow in ways paralleling the infant's development and needs to help the parents facilitate that development. To provide this human relationship we have used both a team and a single primary clinician.

Organizing to respond to a family's concrete needs and offering the family a human relationship, however, are not enough. That human relationship must be able to help the parents understand some of their maladaptive coping strategies and teach them how to deal with their own primary needs and those of their infant. In addition, special clinical techniques and patterns of care, (Greenspan, 1981), to reverse maladaptive developmental patterns in the areas of affect and social interaction, sensorimotor development, and cognition must be available at the appropriate time. Moreover, in our clinical experience, the intervention must occur over a sufficiently long period to allow the family's own strengths to take over and sustain it. We are speaking here then not of a crisis intervention approach over a few months, but an approach that will be available to the families for several years at a minimum. We have found that after working with many of these families for some two years, the mother's capacity to nurture and facilitate the development of new baby is significantly more advanced than when she entered the program pregnant with an earlier child. Our impression is, when the helping relationship is offered over a period of time, the frequently observed trend of multi-problem families to deteriorate further upon the birth of each subsequent baby (a trend that often starts when the parents are still teenagers) begins to be reversed.

In addition, the approach to the multiple needs of these infants and their families must be integrated. Simply offering nutritional advice, (Cravioto, 1980) or educational counsel, providing cognitive stimulation, or taking an entirely infant-centered or entirely family-center approach may not be sufficient. The infants have individual differences that dictate special patterns of care; at the same time, the concerns of their caregivers and other family members have to be addressed. Each stage in the infant's and the family's development requires specialized clinical services and service system approaches (Greenspan, 1981).

Although the costs of offering programs of intervention are great, the costs of not offering them are even greater. The estimated 6 percent of the U.S. population that use 50 percent of all health, mental health, and social services account for economic and social costs that are compounded by the additional loss to society that these people might have contributed to the labor force and to other creative endeavors.

Programs of prevention are expensive, but they are not so costly as might be imagined, since even when services are offered to an entire high-risk community, only a small percentage of the families in that community will actually need the most intensive help. Selma Fraiberg, as director of a Michigan infant mental health program, found that in a program offering a range of preventive services including intensive individual clinical services, the average cost per family participating was $850.[1] In terms of providing screening and backup for an entire community, the cost per family for such preventive services would average out to a significant lesser amount.

Perhaps we need to look at the cost-benefit ratio. Using cases from our own study, we developed a model to project the probabilities (based on observed family patterns and clinical assumptions) of different outcomes with and without preventive intervention. While all projections, as with economic forecasting, are based on assumptions which may or may not be true, the trends we found are of interest. Also this model can be used with other assumptions. Projected benefits outweighed costs by five or six to one (depending on the degree of risk). Interestingly, in the cases at greater risk, in which initial costs might be high, the benefit to cost ratio was often better than in less severe cases, because the benefits of preventive intervention were relatively greater (Greenspan, 1981).

4. *Implications for a Prevention Policy.*—These same principles also apply to less at-risk families. When it has been estimated by the Dept. of Education that 13 percent of our school age children require special services, and informally clinicians and teachers estimate another 15 percent from all social and economic backgrounds could easily benefit from special educational, health and mental health services, the challenges become clear. Too many children from varying social and economic background are evidencing compromises in basic personality functions such as impulse control, self esteem maintenance, capacity to concentrate, to relate warmly to others and even to test reality by the time they reach school. Equal opportunity is not possible for these children as they begin with handicaps, many of which we believe are preventable. Our concepts of education and health care must begin at the beginning when the nervous system is growing most rapidly. (It grows to two-thirds its adult size in the first three years of life.)

A family's "right" to programs that will help them identify lags in their infants' emotional, social, cognitive and neuromotor aspects of development must become a "given" as is the right to education later on. Not all families require the level of effort described earlier. Many families only require help in identifying lags and guidance in providing "special patterns of care" to help their infants function more competently. Other families require the four levels of preventive services described earlier. We must address both needs.

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Mr. LEHMAN. Before we recess to go vote, I would just like to thank the chairman, Mr. Miller, and the staff, for putting together such an outstanding panel. I can't wait to get back for questions.

[Recess.]

Mr. LEHMAN. The committee will come to order.

We will go back to the 5-minute rule. I just have one question, I guess, that Dr. McGaugh can more or less answer. There were four things either you didn't say or I didn't catch. One was the word "mind"; one was the word "dyslexia"; one was the word "computer"; one was the word "stress"—maybe you used them, but practically everyone I hear talk about the brain use those four words.

In your way of thinking, is the mind and brain more or less the same thing, and where does one stop and the other start?

Two, the dyslexia problem, you talk about language but you didn't talk about reading, and I understand that there is no dyslexia in children in Japan, particularly, because they use not linear symbols but other types of characters to read, and so they don't have a reading problem.

And, three, how are we going to be able to better use the computer to get around learning difficulties? Because I have read articles where children with learning difficulties bypass them and work around them by use of the computer. They can't read, but still are making it.

Fourth, stress on the brain—and the kids do have stress. I have seen kids with duodenal ulcers. You didn't say anything about family or community stress, and what effect it would have on the brain. I lost a child with a brain tumor. I understand one of the doctors said it was triggered by some stress that occurred during the period of life earlier than when the tumor appeared.

Dr. MCGAUGH. If I weren't held to the 5-minute rule, I think I could comment on each of those.

Mr. LEHMAN. What you don't cover, I would like you to write me.

Dr. **McGaugh**. Let me try just a couple of things. I think your observation about dyslexia in the Orient is a very good one. It is not well known. It is highly interesting. There may be patterns of information in the environment for which our brains are better prepared. That is, there may be ways in which our brain processes match up well with some kind of information and not with other kinds of information. And one interesting hypothesis about reading difficulties is just that; that there are cultural differences in the extent to which one finds reading difficulties.

Interestingly, there is at least with normal children, raised in normal environments, no such thing as a language disorder. That is, children who are reared in a normal environment learn the language of their adults, learn all the syntax, all the rules and so on without defect. You don't need to have remedial teachers teaching normal children how to speak the language. One has only to deal with the few aspects of grammar and vocabulary and so on. I think that has something to do with the wiring of the brain.

I am glad to say something about stress, because my own research concerns the effects of stress on learning and memory. I alluded to some experiments that we do in my laboratory using hormones to influence learning and memory. The hormones that we use are hormones of stress. We work with adrenaline, for example. We have shown, I think, rather conclusively that hormones that we normally release to ourselves when we learn are hormones which play a critical role in determining how well we will remember the things that led to the hormones' release.

We all know, and educators know, that motivation is important for learning. Our experiments suggest that motivation is important for learning because it involves the release of the right hormones to our brains at the right time.

We can teach laboratory animals tasks that are rather unimportant. If we inject them with the right hormones at the right time, they will remember those tasks as though they had been highly trained.

Now, it is also the case that excessive amounts of these stress-related hormones cause memory losses or memory impairments. If we train animals on tasks that involve a high degree of stress and add hormones following training, we can cause amnesia; we can cause complete memory losses in well trained animals simply by overdosing them with hormones that they normally release to themselves.

What we don't know is whether we have a capacity to overdose ourselves with those same hormones. There are reported clinical cases of people who are, rescued from burning buildings and later have total amnesia for that event. It is possible that the amnesia is due to excessive amounts of hormones released at the time of the experience.

Mr. **Lehman**. There is a possibility that you can teach people to read in Chinese and make a transference to English. Has there been some experience?

Dr. **McGaugh**. Not to my knowledge.

Mr. **Lehman**. As far as the mind goes, do you use them synonymously?

Dr. McGaugh. I don't, because I don't use the word "mind." It is not because I don't think I have a mind or we don't have minds. What——

Mr. Lehman. I was wondering why you left the word out.

Dr. McGaugh. I left it out because what we observe is performance. We observe behavior and we also observe brain function, and we assume they are something in there but that we can't study the mind directly. We can make inferences then about mental processes.

Mr. Lehman. Thank you very much.

The chairman of the full committee.

Chairman Miller. As we review the panel we have just heard from, we see that we have crossed a span from conception to 7 years. In addition, we have specifically looked at the case of alcohol use and prevention strategies. How can we best help the children that fall through the developmental cracks, as it were? I am speaking of those children that don't have full brain development, that don't catch up, that are deprived of the kind of environmental attention that would help their development. Obviously this task force can recommend prevention strategies with regard to alcohol. But in the terms of the other development areas, in brain growth after birth, in enriching the environment of an infant, can we realistically design a realistic prevention strategy?

Dr. Greenspan, your testimony involves a question which has plagued politicians over the last 30 years. That is, what do we do about the welfare cycle, the cycle of underachievers, the cycle of the handicapped? As I understand it, you are suggesting that we can intervene in the cycle, and not only reverse it, but can, in fact, reverse it with the second or third child as well.

Is it realistic for those of us making public policy to gather various strategies whether Federal or not?

Dr. McGaugh. We hear a lot about prenatal development. It is a very important period, from all of the evidence presented here. We also hear a lot of complaints about what is wrong with our high school students or junior high students; what is wrong with their SAT scores; why is education in such a sad condition.

I think that there is one very strong message here. The very early age postnatally are critically important periods. These periods in development have not been sufficiently attended to by public policy. The baby is born and then later is to go to preschool or to enter the first grade. In the meantime, "natural development" will take place. Well, there is no "natural development." There is development, and the development that takes place is subject to a large number of interfering or promoting conditions.

The first thing to do is to focus attention on what might be done in this very critically important postnatal period to assure that problems will not develop. You certainly heard a number of suggestions.

Mr. Lehman. How about greater efforts at prevention in the prenatal and postnatal phases?

Dr. Greenspan. Let me add to Dr. McGaugh's comments. From my testimony, obviously I agree with the implied answer to your question. There is a great deal I think we can do for those who have traditionally fallen between the cracks, because right now we are picking them up at school age for the most part—some in preschool programs—and clearly the consensus of this panel is that that is too late; that the brain structures grow most rapidly from prenatal through the first 3 years of life. Some of these may have the quality of the time bomb that was referred to; in other cases, there may be difficult patterns that are relatively less reversible later on.

We require programs where one identifies babies and toddlers and young children who are deviating either in cognitive or neuromotor or emotional and social development. We are getting better and better in detecting early problems in learning—the babies who can't, for example, coordinate their left and right side give us a picture of the infant form of a learning problem.

Pediatricians for the most part are too busy to do these kind of tests in an office practice. Many people can't afford to get the kind of assessment that would offer them appropriate early detection of these kinds of problems.

For minimum motor problems to early preverbal language problems, we can do better. We for example can trace the development of language from 4 or 5 months with the types of syllables that babies can utter. We can detect if the baby is going to have a language problem way before the youngster becomes 3 and the parents say, "John is not talking."

So we need early identification, but not superficial. We have to have a large net. It then has to be backed up more definitively with diagnostic approaches behind it. Then to have graded levels of services. Sometimes just advice to the family that this baby is hyperactive to sound is needed. If you do it this way, your baby will begin attending and orienting and won't be distracted, won't be looking away, and you will probably reduce the likelihood this baby will be a distractable baby.

Another group of families are going to need ongoing work. A third group will need comprehensive programs that have three levels: concrete services dealing with survival issues, ongoing human relationship, and the technical approach to work with the baby and the family over a period of probably years. But when you look at what it costs for one of these children who doesn't make it into society, you are talking about a discounted cost of probably $400,000 over the lifetime of this child. So even if the program costs for the most expensive youngster $5,000 a year, to make sure that that youngster starts out competent, it is enormously cost effective over the long haul.

But no question that we have enough knowledge now to do much more than we are doing, and we ought to be gearing enormous amounts of research into this area of prenatal care and care in the first 3 years of life, so we can learn more and do more.

Dr. **Falkner.** I would like to add very briefly, I couldn't agree more with my colleagues. I would like to get back on my hobbyhorse and make a plea for us to investigate the fetus who falls through the cracks. It is often too late to intervene when faced with a damaged newborn, the damage or nonintactness having been perhaps prenatally caused.

As regards research, what we do need, I think, is a great deal more research on fetal growth. We need to monitor this. We can in someways do so now, yet we need much more information so that we can then answer such questions as: Why is a baby born prematurely? Why is a baby born small? We don't really know.

Chairman MILLER. My point in raising this question is to draw out from each of you rational and realistic—in terms of our ability to deliver—prevention strategies that could take place at the earliest levels of development, whether it is during the fetal period or with the toddler. It seems to me you are each suggesting there are.

I ask because there was an earlier comment with regard to infant mortality suggesting we are doing about as well as we can do because we have to understand more. It is my concern that before we get into the mysteries, we should look to those things we already know work, whether in the particular case of alcohol and pregnancy. We know abstention in that case will prevent many problems. We ought to know whether we are doing all we can do in other areas as well.

Dr. McGAUGH. I would like to say a word in behalf of mystery, though; that while I agree with precisely——

Chairman MILLER. I have to be careful. I am not against research.

Dr. McGAUGH. Thank you.

The reason I say that is because, as we all know, the social behavioral sciences have taken it in the necks in recent years with respect to cutbacks in funding, targeted cutbacks of funding in the areas we are talking about, social and behavioral research. And I will add to that the neurobiological research related to that, which is key to providing the further understanding which will lead to the next step in the prevention. And I would strongly suggest that that was a very, most inappropriate place to be taking cuts in the research budget.

Chairman MILLER. One of the things we hope to gather from the work of the select committee and its various task forces, is to take what we've learned and offer a range of policy considerations for Congress. Whether they chose any is not the business of this committee. If we can demonstrate a working knowledge of strategies for prevention and crisis intervention to name two, then Congress can choose from among those various strategies if it chooses to.

Obviously, in some areas it will simply be that we need to know more. But we are trying, as well, to correct the more immediate concerns with knowledge that we already have, so that we can make some suggestions for solving the problems. Whether that comes to pass or not is a decision that the Congress of the United States will make.

It will be very helpful if after you get done testifying, we can come back to you and for suggestions you would make in the area of prevention strategies, whether they are for the private sector, public sector or a combination thereof.

Thank you very much.

Mr. LEHMAN. Mrs. Johnson?

Mrs. JOHNSON. I am very sorry that I missed the rest of the panel's presentation but I have enjoyed reading your testimony. However, in skimming it and following up on the Chairman's questions, I have a few questions.

You referred to things about your observation in cases by helping the mother and family with one child, that changes are possible. In Connecticut, we have had a number of crisis intervention programs developed that involve parent aid. The presence of someone in the family, very early intervention form, and very heavy emphasis on teaching, parenting and nurturing, has made a difference, and I wonder, through your work, what specific programs in the years before 3 have you seen having the greatest effect?

Dr. **Greenspan**. There are two programs right in your State, in Connecticut. There is the University of Connecticut Health Center that had an innovative program using lots of outreach workers, and I can put you in touch with the people doing the research. They have had follow-up now for a couple of years, showing positive effects on both the children and the families. There was a study done at Yale where they now have a 10-year follow-up. They worked a large poverty sample that had family problems but not the most severe (i.e., the ones that really fall within the cracks), and they offered preventive intervention strategies, guidance for children, support for parents, skills and parenting, identifying individual differences in babies, such as picking out the baby who is hyperactive, those who needed extra wooing and so forth.

The results 10 years later suggest not only babies and children doing better, but also less need for special services in school, 50 percent less in the group having the intervention than the group that didn't have it. The families are doing better. Fewer of them are on welfare; more are self-supporting.

There are other findings suggesting long-term benefits to both the children and the families. And the programs that seem to work the best are those that work at both levels, the child and the families, because then the family is able to carry on new competences to not only that child but to the family in general.

Mrs. **Johnson**. Have you looked at the Head Start program in terms of your work?

Dr. **Greenspan**. Well, I have been in touch with the people who have been looking at the Head Start program and the long-term results.

Mrs. **Johnson**. Are there ways that you should be effecting their approach to parents in the early years, on the basis of the information that you developed to alter their approach? That certainly seemed to be one of the most effective instruments, although perhaps not starting young enough.

Dr. **Greenspan**. In Head Start, as you know, one of the dramatic benefits was in family attitude, family patterns. That goes along with all of the evidence now that is emerging about which programs work the best. It is those that do help the whole family. I would like to see Head Start to become "early—start". And I would like to see the Head Start use what it has learned by offering intellectual support for the children, use that as an entry for all kinds of health and mental health services to the family, including the emotional problems of the family, including following the emotional milestones of babies, because babies and children don't separate out how they deal with the "feelings" and how they deal with the A, B, and C's. If "feelings" confuse them, you get chaotic behavior instead of organized behavior, and you have societal problems.

So my hunch is we should use the evidence that Head Start helped the families and play on that strength, and let's use that opening to address all families on developmental needs, which includes all lines of development from physical to cognitive and emotional.

Mrs. **Johnson**. Are there other specific programs that you would recommend we look at?

Dr. **Greenspan**. Yes, I have a list that I can send you.

Mrs. **Johnson**. Did you address that earlier?

Dr. **Greenspan**. No, that is not in the testimony. We can prepare a summary statement of some of the model programs.

Mrs. **Johnson**. I think I would be very interested in that.

Dr. **Greenspan**. The National Center for Infant Programs could help put that together.

Mrs. **Johnson**. The other thing that follows from that which you referred to a moment ago is how much do we know about the need of these children for special education. You also say that we need to rethink our basic philosophy, and I think there is a lot of sense in that, particularly in light of what you say.

If we need to go to early intervention and a whole different support system and effort to effect development, then what does that say about development after age 7? How many resources does that have implications concerning our approach in special education? Should it be blanket? Should it be blind to individual differences? Are there alterations we ought to make? Are there resources we ought to target to some kind of population, or should we continue along on the sort of broad equal opportunity generalized approach?

Dr. **Greenspan**. I am suggesting, we are not offering equal opportunity now. When we started at age 5 and 6, the kids are not equal any more, and by giving them a little bit of school—because the school resources are so slim—most of the children don't get what they need in terms of special education by the time they are in school. We need to target special educational approaches to the first 3 to 5 years of life when it will have more impact. But we need tc continue it, obviously, once the children are in school. Some will need continuing help.

But we will probably get more bang for the buck if we can target it earlier and earlier in the life cycle; not wait until these children have severe problems and have to fight an uphill battle. The kids who are in special education, a high percentage have severe emotional problems. You are fighting a double battle by that time and we believe these problems can be identified much, much earlier.

Mrs. **Johnson**. Just finally, I'd like to ask two more questions. First of all, in talking about the impact of alcohol, have you done any study about the impact of marihuana?

Dr. **Greenspan**. Someone else may address that. I haven't.

Mrs. **Johnson**. It is certainly a significant alteration in fetal development environment.

Dr. **Ouellette**. In terms of prenatal attention to marihuana, there is a recent study out of Boston City Hospital written up in Pediatrics in October 1982, which indicated that if marihuana was used less than three times a week, that the babies were about 95 grams smaller than the woman who did not use marihuana; used more than three times a week, they were 139 grams smaller. So there was an effect of marihuana on size of babies.

They also found that if the women were drinking alcohol and were using marihuana, that they had a much higher risk of having abnormal children than if using either of these drugs alone. That is the work that I am familiar with.

Mrs. JOHNSON. It would be interesting to have summaries of that work.

I wonder how much has been disseminated?

Dr. OUELLETTE. It is a fairly new work.

Mrs. JOHNSON. Is there any examination of those things on the development of fetus and particularly of brain size?

Dr. OUELLETTE. I don't know that there is really any data on that. There may be some animal research, but I am not familiar with it. I can look it up.

Mrs. JOHNSON. Would you check that out?

Dr. OUELLETTE. Yes.

Chairman MILLER. Nothing comparable to the work done on alcohol?

Dr. OUELLETTE. Nothing at all.

Mr. LELAND. I apologize to the other panel, Dr. Greenspan, because I have been running in and out and missed your testimony. You say something that interests me considerably. I have been working with the issue of teenage pregnancy in Houston for some years now, and one of the things that I am finding as we discuss this issue, is the dichotomy between the white families and black families, the black families and Hispanic families, all of those among different groups in their handling of the pregnancy. One of the things I found is that there is a very limited conceptualization of the extended family in the black community and, thus, when these young girls bear children there is considerable indifference displayed by the family as a result of the pregnancy, and there is a tendency for the black mother or the black father to turn on the young girl. In addition to these family conflicts, society places pressure on the young girls as well.

The teenage girl becomes depressed over a long period of time. That depression probably is transferred to the child that she eventually bears. Further, this syndrome may be repeated by these particular young girls.

Can you just comment on this cycle in terms of the development of the child from birth of the baby?

Dr. GREENSPAN. We had a chance to work with a number of young adolescent mothers, and we have seen both family patterns—both the one you mentioned—it is not limited only to certain ethnic groups; it is independent of race—but there are some families very rejective, who put a lot of pressure on the adolescent mother, offer very little support. They often get out of the house, move into the boyfriend's, into the cycle of chaotic relationships, often on to have another child, which does worse than the first, and they seem to fit the pattern of these multirisk families which often start their childbearing in adolescence, and each subsequent pregnancy the mother and child do worse and worse and worse. And you may have five or six children in the same family.

In other families, there is another interesting pattern observed where the daughter is embraced by the family and the care of the baby is somewhat taken over by the baby's grandmother or the young girl's mother. Often they want to get rid of the boyfriend.

Mr. **Leland**. Is there an ethnic comparison there?

Dr. **Greenspan**. I don't have the data for the ethnic comparison. I have seen it across ethnic groups in a few cases we had observed a mother who is covertly encouraging the daughter to have a baby for a variety of often unconscious reasons.

Mr. **Leland**. That is a dangerous area to tread.

Dr. **Greenspan**. Yes.

Mr. **Lehman**. We are going to recess now to make our vote, and then we are going to recess until 2 o'clock, and we will come back.

I just really have appreciated your being here. At 2 o'clock, we will have panel No. 3, and we will continue the hearings at that time.

[Whereupon, at 1 p.m., the task force recessed, to reconvene at 2 p.m., the same day.]

AFTERNOON SESSION

Mr. **Lehman**. The committee will come to order

We now have panel No. 3. I don't know whether you all want to read separate statements or not, but if you do, we would appreciate it if you would summarize them and we will put the full statement into the record.

On the schedule, we have Angela Blackwell and Lois Salisbury, introduced by Dr. Falkner. Please proceed.

Mr. **Falkner**. Mr. Chairman, members of the committee, it is my pleasure to introduce Angela Blackwell and her team to you. The reasons I am doing this introduction is simply that her organization approached the School of Public Health at the University of California, Berkeley, and specifically my department, ask for input from the scientific point of view in their collection of data. The team involved in the University of California, Berkeley, is—apart from myself—Dr. Jeffrey Gould and Dr. Peter Budetti, who have in fact directed the analysis and data-gathering for Angela Blackwell and her team.

Mr. **Lehman**. Thank you.

STATEMENT OF ANGELA BLACKWELL, ATTORNEY, PUBLIC ADVOCATE, CALIFORNIA

Ms. **Blackwell**. I am happy to have the opportunity to present information before this panel. I am speaking on behalf of the organizations for whom we filed an administrative petition with the Health and Human Services yesterday regarding prevention of low birth weight and infant mortality. They are listed in the testimony but include among others the National Urban League and the NAACP-Western Region.

Included in the petition are several pieces of information I want to discuss. One is the study that Dr. Falkner mentioned. It is a survey of 45 cities that examined infant mortality, low birth weight, teenage pregnancy and prenatal care in those 45 cities for the years 1978 through 1981.

Before I give you the results, I want to provide a little background information so you will understand the importance and the magnitude of the study.

In looking at infant mortality, for the 45 cities we looked at an average of 225,000 births for blacks each year and 376,000 births for whites. The approximate number of black births in a year is about 500,000. Our study included one-half of the black births per year for the years studied.

Also, in reporting the averages for the survey, we used weighted averages so we were able to take into account the differences in fluctuation in infant mortality rates for small cities and large cities. You don't want to compare Youngstown, Ohio, to New York City. We used all live births and all deaths to obtain weighted averages.

Also, I think it is important to note that all the statistics used were final statistics for those years. It was not provisional data. What we found was that, consistent with the trend we have seen nationally, there is a widening gap between infant mortality rates in the white community and infant mortality in the black community.

We also found it very difficult to obtain data. We called the National Center for Health Statistics from the very beginning to find out what was available there and if we could get any data broken down by race beyond 1979. This morning Dr. Brandt gave final data for 1980 which is the first time we have been able to get that information. I called the National Center for Health Statistics the day before we left California just to be sure there was still nothing available. So, I was very pleased to get those data.

That data are consistent with the trend we document in the petition which is that in 1950, the infant mortality rate in the black community was 64 percent higher than the infant mortality rate in the white community. By 1970 the infant mortality rate in the black community was 83 percent higher than in the white community. In 1979, the last year for which we had data as of early this morning, the infant mortality rate was 91 percent higher. The data that Dr. Brandt gave this morning confirmed that as of 1980 the infant mortality rate was 94.6 percent higher in the black community than in the white.

In our study of 45 studies, the differences ranged from 70 percent higher in 1978 to 82 percent higher in 1981. Consistent with what Dr. Brandt said this morning, it does appear that there has been a slowing in what the medical community can do to further bring down infant mortality rates by saving small babies. What we are seeing now is that even at the national level, there has been a slowing in the reduction of infant mortality. Therefore our information has focused on low birth weight, the biggest contributor to infant mortality and the one area in which we have seen very little change over the years.

In our study, in 1978, the low birth weight rate among blacks was about 13 percent and in 1981 it was still about 13 percent. In fact, it has gone up from 1980 to 1981. The focus now should be on how to prevent low birth weight. Therefore we examined those factors that contribute to low birth weight.

Many things do. The factors we were able to obtain data on were teenage pregnancies and prenatal care. We found that the teenage pregnancy rate was going down for blacks and whites in the cities surveyed, but the gap was widening. There was a 118 percent higher teenage pregnancy rate in the black community than in the white community in 1981. Very disturbing was the information regarding prenatal care. Unfortunately, the cities for which we were able to get prenatal care data were limited. We had only six cities. They were large and are indicated in the back of the infant mortality petition you have in front of you.

We found, for black and white women, the percentage of women getting prenatal care in the first trimester was going down, and for black and white women, the percentage of women getting no prenatal care was going up. There data are very disturbing because they indicate that no progress is being made in this country in terms of alleviating the factors that contribute to low birth weight and therefore low birth weight is remaining constant.

Another very interesting aspect of our study was that in the cities the white population in general was not faring as well as the white population in national statistics. For 1978 and 1979, the years for which we had duplicated data for the cities and from national sources, we found the white rates in the cities were higher than the national rates. We also found the black rates in the cities were a little lower than the national rates. That is why in the cities there is a smaller gap than found nationally.

For example, I said that in 1981 the black infant mortality rate was 82 percent higher than the white rate. At the national level it was 94 percent higher. This is really a confirmation of what we are presenting today, that low-income women are having the most difficult time getting the services that are needed to prevent low birth weight. We see higher white rates in the cities because we have larger concentrations of low-income white women. We see slightly lower black rates in the cities because there is a higher concentration of middle-income black women—more poor white women, and more middle-income black women. That confirms it is the low-income woman that is suffering the most. Our data are presented in terms of blacks and whites, because we were unable to get statistics broken down by Hispanics, poor whites, Asians, and others. The real point of our petition is that the low income, the poor, those who lack access to prenatal care, are suffering the most.

The other piece of information we think should be of interest to the committee is the cost effectiveness of solving this problem. We propose that prenatal care can do something about low birth weight. My partner, Lois Salisbury, will talk about that in more detail. What I want to share with you is the result of the cost effectiveness analysis developed with Carol Korenbrot and Peter Budetti with the Institute for Health Policy at the University of California.

The cost effectiveness analysis compared what it would cost the Federal Government to provide comprehensive prenatal care to all low-income needy women with what it presently costs the Federal Government to provide neonatal intensive care and rehospitalization in the first year for the babies that are born of low birth weight. As a result of our study, we found that for every dollar spent on comprehensive prenatal care, the Federal Government can save $3. The exact figures are listed on page 120 of the petition.

It currently costs the Federal Government $638,346,300 to provide neonatal intensive care and rehospitalization in the first year of life. After providing comprehensive prenatal care, the Federal Government could save over $500 million. That is the initial savings. If you subtract from that what it costs to provide comprehensive prenatal care, over $360 million can be saved each year. That is a minimum figure, because what we have looked at is just the cost of providing care in the first year.

The analysis does not include long-term costs. It doesn't include the cost of institutionalization that can range anywhere from $300,000 to $1 million per case. It doesn't include the cost of physical handicaps, other rehospitalization after the first year, or the emotional stress and strain that just comes from trying to care for a child that is not normal. This savings is the minimal savings that the Federal Government can produce by providing comprehensive prenatal care.

I will let Lois Salisbury talk about comprehensive prenatal care and the exact recommendations we propose.

Mr. **Lehman**. What you said, though, is that the higher the family income, the more babies are all right.

Ms. **Blackwell**. Unfortuantely, the things that correlate with the low family income are lack of prenatal care, lack of nutrition education, and lack of access to medical services.

Mr. **Lehman**. What is said is correct, basically. There is a direct correlation.

Ms. **Blackwell**. Unfortunately, that is true.

STATEMENT OF LOIS SALISBURY, ATTORNEY, PUBLIC ADVOCATE, CALIFORNIA

Ms. **Salisbury**. Dr. Brandt left us this morning with the impression that perhaps we were doing well in our progress toward reaching the 1990 goals set by the Surgeon General. However, I conducted a quick analysis based upon the new 1980 data we were finally able to learn from Dr. Brandt this morning, even though we were not able to obtain it until just several days ago.

If, based upon the black and white national statistics that Dr. Brandt gave us, we ask how well are we doing in reaching our 1980 goal, the white population, in striving to reach an infant mortality rate of 9 per 1,000, is 82 percent toward its goal. The black population is 42 percent toward its goal. Even if we accepted the higher minority mortality goal that, in recognition of the tremendous gap between black and white infant mortality rates, the Surgeon General recommended, the black population is only 56 percent toward its goal versus 82 percent for the white population.

As other experts have said, and as our document makes clear, when we focus on the low income minority population, low birth weight is the problem. It is the high incidence of low birth weight, the fact we have so many small babies to save, that makes the United States' standing internationally so poor, when one would expect that a country with our technological know-how and with our resources, would do well.

In fact, we don't stand well. It is simply because we don't have the commitment to prevent small babies. We do know how, when we apply what we know. In fact, Dr. Brandt left us with the impression this morning—and I was somewhat surprised he did so—that we needed to conduct more research to find out how to prevent low birth weight babies, and that research grants had been expended on that.

While I don't fault the expenditure of research money, I think the answer is much better known and better established within the medical literature than what he conveyed this morning. The medical literature is replete with examples of comprehensive prenatal care which has dramatically reduced the incidence of low birth weight, and in turn, has reduced the tendency of high infant mortality among low income minority communities and also especially among teenagers. I would like to provide you a few of the examples cited in the petition.

In St. Paul, Minn., a program which was comprehensive and provided teenagers prenatal care through their school, effectively reduced the low birth weight rate from 13.9 percent down to 5.5 percent.

In 1972, a program built upon the talents of nurse/midwives in rural Georgia, halved the low birth weight rate from 24 percent to 13.8 percent.

In California, a project over the past several years which was designed particularly to reach women who lived in 13 underserved counties was able, again, virtually to halve the low birth weight rate from 7.3 percent down to 3.9 percent.

In the South Bronx—an area I suspect I don't need to tell you very much about in terms of the many poverty indicators which are there—at Lincoln Hospital, a program designed for teens reduced the low birth weight rate from 18 percent down to 3.6 percent.

Most of these rates, then, are well within the range that the white population is presently enjoying. Prenatal care has been shown effective in bringing those rates down for low-income minority populations, even for teenagers, which are considered to be one of the most high-risk components of the population.

A project in Oakland, Calif., again serving low-income minority populations, found a very interesting correlation between the number of prenatal visits a woman experienced and the birth weight of her baby. For a woman who had more than 10 prenatal visits—and the standard prescription of medical care by the American College of Obstetricians and Gynecologists is 13 visits—the low birth weight rate was 3 percent. Bear in mind the national black average is 13 percent. For those women who enjoyed five to nine prenatal visits, the low birth weight rate was still well below the national average, 10.1 percent. For those with less than five visits, it was 12.4 percent.

All of these programs provided what is called comprehensive prenatal care and that label, comprehensive, is there to distinguish it from what you might call the more usual or standard prenatal care which includes visits to the doctor, the checkups, the blood pressure readings, the various analyses that are conducted.

Comprehensive prenatal care also includes psychosocial assessments, nutritional assessments, as well as health education, all of which, as Angela Blackwell set forth, has been found to be tremendously cost effective. The ratio is for every dollar spent, $3 will be saved in preventing neonatal intensive care and rehospitalization during the first year.

These findings that I reported to you, in fact, have not only been part of the medical literature but were part of major governmental reviews, three of which were conducted in 1980. During 1980, the subject of maternal and child health and prevention was of much concern to the Comptroller General, the Surgeon General, and Congress own Select Panel for the Promotion of Child Health.

Each of those three committees found that while we didn't necessarily understand why prenatal care is so effective, it is without doubt effective in dramatically reducing the rates of low birth weight among low-income families and, therefore, greatly impacting on our high infant mortality rate.

The wherewithal, the knowledge, is well within our control right now. We don't have to deal with mysteries. Prenatal care works and while it would be fascinating to know more about why, we do know that the comprehensive package is unquestionably effective.

There were questions this morning addressed to Dr. Brandt and the other panelists about the present status of Federal programs and what can be achieved through them for low-income women. Because of those questions, I would like to take a moment to let you know what we—in behalf of the organizations listed on the front of our petition, which are civil rights organizations, such as the National Urban League; women's organizations, such as the NOW Legal Defense and Educational Fund—what it is we have asked the Reagan administration in our formal rulemaking petition to initiate in order to close this very sadly widening gap between the black and white infant mortality and low birth weight rates.

One of the most basic problems is that there are an enormous number of women who do not have access to prenatal care through medicaid at this point. They are poor women, they are known to be left out of medicaid in many States. The number is difficult to calculate, but is estimated at a minimum to be 220,000 based upon Congress work having to do with the CHAP bill.

Most of those women fall into one of two categories that are denied of access to medicaid, categories which have been recognized as being particularly absurd as a basis for policy. One is first-time pregnancies. Nineteen States do not provide medicaid for first-time pregnancies. Therefore, prenatal care is not available under the Medicaid program for women who are undergoing their first pregnancy because it is tied in with their eligibility for welfare. That categorical eligibility link puts us in the absurd situation where we pay for the birth, which may include intensive care, but we won't pay for the prenatal, preventive care. We are not being cost effective in what we do.

Another major category includes poor women who come from famlies with two spouses, where you have a working spouse, maybe two working spouses, but even so, their combined income leaves them very poor. They cannot afford medical care. Prenatal care is not available to them under medicaid again, because they are categorically linked to welfare, and two-spouse families are not eligible. The minimum total figure is 220,000 and that was the 1979 estimate. It could be greater.

The fact is that this Congress, in 1981 and 1982, passed amendments which would allow the States, particularly States which are feeling their own fiscal pressures, to be both fundamentally concerned with the health of their population and also to be cost effective, to expand their medicaid programs, to include coverage for exactly those categories I just described who are now left out. But the current administration has failed in any way to exercise leadership and encouragement to the States in spelling out their options under those recent amendments, so that the States are fully informed of what they can do if they want to prevent low birthweight, if they want to maximize their own health dollar expenditures.

Those particular options, then, are one of the major remedies we have proposed. We have asked the Federal Government to spell out in technical regulations exactly what the State's options are and to encourage the States to exercise those options because of their ultimate wisdom for both the health of our citizens as well as for our fiscal vitality.

We have also asked that there be the establishment of a select coordinator. Every one of those major 1980 governmental reports I cited to you acknowledged the fact our current Federal programs, including maternal and child health, medicaid, some of the other programs, are woefully uncoordinated, resulting in inadequate care, duplication of services in some instances, and complete gaps in others.

The Federal role in material and child health has been notoriously inefficient. Yet there is no one person in HHS who has oversight over all of the maternal and child health care questions. They are spread out in a lot of different places. It is that lack of oversight and coordination which has resulted in great confusion for the States and certainly a lack of priorities in understanding how to spend the allocated Federal dollars.

Another major program that could be particularly helpful in addressing the problems of teenagers is the early and periodic screening diagnosis and treatment program (EPSDT). Right now teenagers do not, at least not by Federal mandate, obtain OB/GYN services or family planning services through this program, should they be pregnant. Yet EPSDT is an obvious vehicle, one with which I am sure some of you are familiar in terms of its tremendous impact on children, to make sure that if a teenager is pregnant she receives good prenatal care and that all eligible teenagers receive family planning services which might prevent the pregnancies in the first place.

Another major component of what we asked for is an education campaign. We have heard a lot of discussion this morning about the value of an education campaign. We couldn't agree with what's been said more. I think, perhaps, what we might disagree with is whether it is wise to engage in an educational campaign focused particularly on low income women if, in fact, we are not willing to make the companion commitment to make sure they have access to prenatal care or can afford prenatal care. To encourage women to find prenatal care and to appreciate its importance, but then not to provide it strikes us as inhumane.

A national education campaign is needed. Probably the best prevention campaign most of us experienced in our growing up years was the Smokey the Bear campaign. We are asking that the same wisdom and the same application of resources—billboards, television, radio—be directed at the low income community so that they are particularly taught that valuable preventive lesson we know can come from prenatal care.

The fact is that the current administration is trying in some manner, in conjunction with the 60 organizations who are participating in the healthy mother-healthy baby campaign, to begin to get that message out. I would like to share with you one of their major public relations posters, at least to alert you to the fact that it is possible they are distinctly out of step with what needs to be done.

This is the healthy mothers-health baby campaign poster. What you can see is that it is a woman standing—she is pregnant, moderately pregnant, and is in a gauzy negligee, nightgown, or evening dress. She may or may not be of minority status. She is pushing a white wicker sort of combination baby carriage, supermarket basket overflowing cornucopia style with food, including milk in a bottle, French bread, glorious fresh fruits. While this is a lively image in a fantasy world, it does not speak to the reality of what most low-income women are experiencing in their day to day lives, either how they have to dress or where they shop.

Our clients are, needless to say, quite critical of the fantasyland presented here when the message we are trying to get to the low-income community, to the minority community, is such a real one and right now is such a harsh one.

This is put out by the Federal Government. This is healthy mothers-healthy babies, the campaign Dr. Brandt was discussing this morning.

Mr. LEHMAN. Our tax money is paying for that?

Ms. SALISBURY. Yes. At least it shows that a national education campaign can be conducted. We do believe there is a tremendous amount on an interim basis that the current administration could do to assure that prenatal care is available to all low income women. It is also cost effective to do so, as indicated in the cost effectiveness analysis Angela Blackwell set forth. It could be done and save the Federal Government money, even though comprehensive prenatal care, as opposed to standard prenatal care, costs a little more to provide. The savings in the long run would be well worth it and would bring down total medicaid expenditures.

There are also, of course, many things that Congress can do. The kinds of proposals we outline in our petition are directed to the administration because they are available and can be done quickly and depend upon leadership. Those same proposals, however, newly set forth options to the States. It may be, at some point, Congress will decide this matter is so important it should not be a question of options, that it should be mandatory. That is the range between the administrative remedies and the legislative remedies you might be considering.

Thank you.

[Prepared statement of Angela Blackwell and Lois Salisbury follow:]

PREPARED STATEMENTS OF ANGELA BLACKWELL AND LOIS SALISBURY, PUBLIC ADVOCATES, INC., IN BEHALF OF: NATIONAL URBAN LEAGUE; LEAGUE OF UNITED LATIN AMERICAN CITIZENS; N.O.W. LEGAL DEFENSE AND EDUCATION FUND; NAACP—WESTERN REGION; NATIONAL COUNCIL OF NEGRO WOMEN; BLACK WOMEN'S NATIONAL HEALTH NETWORK; COALITION TO FIGHT INFANT MORTALITY; NATIONAL BLACK CHILD DEVELOPMENT INSTITUTE; AND OAKLAND PERINATAL FORUM

I. EVERY SIGNIFICANT INDICATOR REVEALS A WIDENING GAP BETWEEN THE SURVIVIAL PROSPECTS OF BLACK AND WHITE INFANTS

There is an infant death gap in this country, and it is widening. For years, Black babies have died before their first birthday at a rate that has far exceeded that of white infants.

This infant death gap has been an expected—and in many ways accepted—statistic due to its consistency over the years. In 1950, the Black infant death rate (43.9 per 1,000 live births) was 61 percent higher than the white rate (26.8 per 1,000 live births). By 1979, the Black rate (21.8) was 91 percent higher than the white rate (11.4).

Public Advocates, in conjunction with the University of California School of Public Health, at Berkeley, conducted a survey of 45 cities to obtain 1978-1981 data broken down by race, data not currently available from the National Center for Health Statistics. Measuring various factors related to infant mortality, the data showed a widening gap between the Black and white survival rates: the 1979 gap was 71 percent (21.27 vs. 12.36); the 1980 gap was 73 percent (20.25 vs. 12.62); the 1981 gap was 82 percent (21.13 vs. 11.58); in 32 of the 45 cities, the Black rate was more than 50 percent higher than the white rate; and in 15 of the 45 cities, the Black rate was more than double the white rate.

Nearly two/thirds of U.S. infant mortality relates to low birth weight. A baby weighing less than 2500 grams (5-1/2 pounds) is at significantly greater survival risk than a larger infant. Low birth weight is widely recognized as the primary contributing factor to the relatively high U.S. infant mortality rate, and to the racial infant death gap. While much can be done successfully to prevent low birth weight there has been, in fact, no progress in recent years; if anything, new data suggest that the incidence of low birth is beginning to rise again. The 32 cities which kept low birth weight data revealed: in 1979, the gap was 94 percent (13.13 percent vs. 6.7 percent); in 1980, the gap was 90 percent (12.78 percent vs. 6.7 percent); in 1981, the gap was 92 percent (13.08 percent vs. 6.8 percent); of the 32 cities which maintain low birth weight data, 47 percent showed an increase in their rate for Blacks from 1980 to 1981.

For very low birth weight babies, (those at greatest risk, less than 1500 grams), the increased incidence was dramatic: 1979, the gap was 86 percent (2.57 percent vs. 1.3 percent); 1980, the gap was 105 percent (2.47 percent vs. 1.2 percent); 1981, the gap was 132 percent (2.72 percent vs. 1.17 percent).

Translating these data into real numbers, (assuming approximately 500,000 Black births a year) a Black low birth weight rate of 13 percent means that 65,000 Black babies per year are beginning life in very adverse cirumstances. Many will die; many others will bear lifelong consequences.

II. PRENATAL CARE EFFECTIVELY PREVENTS LOW BIRTH WEIGHT AND RESULTANT INFANT MORTALITY

Given the United States technological know-how, this country should be at the top of the list in terms of saving the lives of small babies. In fact, the United states saves small babies on a par with any country in the world; the infant mortality rate remains high because the U.S. has so many small babies to save. Something can be done about it. The petitioning organization seek something to be done about it now and that policies be put in place to immediately reduce the high low birth weight rate which particularly affects minority, low income communities.

Medical literature and several major studies initiated by the Federal government have made it abundantly clear that the incidence of low birth weight can be drastically reduced through early comprehensive prenatal care. For example: in St. Paul, Minnesota, the maternal infant care program reduced the low birth weight rate in the high risk area from 13.9 percent to 5.5 percent. In a rural area of Georgia a prenatal program nearly halved the incidence of low birth rate in that region from 24 percent to 13.8 percent. In Lincoln Hospital in the Bronx, New York, comprehensive prenatal care reduced the low birth weight rate by two-thirds from 18.1 percent to 6.3 percent in the prior year.

III. PROVIDING PRENATAL CARE IS COST EFFECTIVE

Not only are there proven methods of reducing the incidents of low birth rate and resulting infant mortality, but these methods have proven again and again to be cost effective. Petitioners' analysis shows that the federal government can save $361,081,220 by providing comprehensive prenatal care to all low income women.

The cost savings figure was computed as follows: It currently costs the federal government $638,364,300 to pay for neonatal intensive care (NICU) and rehospitalization for low birth weight infants during the first year of life. This figure could be reduced to only $90,199,040, if comprehensive prenatal care were available to all low income women. The additional expense of providing such comprehensive prenatal care is $187,084,040. By substracting the cost of the additional coverage ($187,084,040) from the projected savings of $548,165,260, a final cost savings figure of $361,081,220 is obtained.

Current federal cost for NICU and rehospitalization	$638,364,300
Federal cost after providing comprehensive prenatal care	−90,199,040
Total	548,165,260
Federal cost for providing comprehensive prenatal care	−187,084,040
Savings to federal government	361,081,220

IV. ADMINISTRATION REMEDIES PROPOSED BY PETITIONERS COULD INSURE PRENATAL CARE FOR ALL POOR, PREGNANT WOMEN

The current Medicaid law, with proper leadership and encouragement from this administration, could insure prenatal care for all poor, pregnant women. Petitioners propose that the Reagan administration take immediate action. Health and Human Services should do the following:

Appoint a Select Coordinator to oversee all existing federal programs in maternal and infant care;

Develop an education campaign that will inform women of the importance of prenatal care and make the need for prenatal care as well known to low income Americans as Smokey the Bear's "You Can Prevent Forest Fires" is known in every American home;

Encourage states to expand their Title V and Medicaid programs so that they can efficiently provide comprehensive prenatal care to all financial-needy families and begin to control the problem of teenage pregnancies by providing pregnancy prevention information and prenatal care to teenagers, if they become pregnant.

AN ADMINISTRATIVE PETITION TO
THE UNITED STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES

BLACK WOMEN'S HEALTH PROJECT/NATIONAL WOMEN'S HEALTH NETWORK;
COALITION FOR THE MEDICAL RIGHTS OF WOMEN;
COALITION TO FIGHT INFANT MORTALITY;
FAMILY PLANNING FORUM;
FOOD RESEARCH ACTION CENTER;
LEAGUE OF UNITED LATIN AMERICAN CITIZENS;
MEXICAN-AMERICAN LEGAL DEFENSE AND EDUCATIONAL FUND;
NAACP-Western Region;
NATIONAL BLACK CHILD DEVELOPMENT INSTITUTE;
NATIONAL COUNCIL OF NEGRO WOMEN;
NATIONAL URBAN LEAGUE;
NATIONAL WOMEN'S HEALTH NETWORK; and
N.O.W. LEGAL DEFENSE AND EDUCATIONAL FUND,

Petitioners,

vs.

SECRETARY OF HEALTH AND HUMAN SERVICES, Margaret Heckler,

Respondent.

ADMINISTRATIVE PETITION TO REDUCE THE INCIDENCE OF LOW BIRTH WEIGHT AND RESULTANT INFANT MORTALITY

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The cost effectiveness analysis was modeled after the methodologies of Dr. Carol Korenbrot and Dr. Peter Budetti, both of the Institute for Health Policy, University of California at San Francisco, who also personally reviewed our work.

The remedies section was prepared with the ongoing advice of Sara Rosenbaum, staff attorney with the Children's Defense Fund and was substantially drafted by Abby Cohen, staff attorney with the National Childcare Law Center.

Our support staff, Gloria Kennard, Roberta Bull, Judy

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I. INTRODUCTION

There is an infant death gap in this country, and it is widening. For years, Black babies have died before their first birthday at a rate that has far exceeded that of white infants.

This infant death gap has been an expected--and in many ways accepted--statistic due to its consistency over the years. In 1950, the Black infant death rate (43.9 per 1,000 live births) was 61% higher than the white rate (26.8 per 1,000 live births). By 1979, the Black rate (21.8) was 91% higher than the white rate (11.4).

While there has been improvement in the overall infant mortality rate and while white infant mortality has reached a level that some in the nation are satisfied with, the infant death rate for major sectors of society remains deplorable. Moreover, the infant mortality rates among Blacks in major cities throughout the United States in 1981 (the last year for which data are available for most cities) were equal to and in some instances higher than the infant mortality rate of whites in 1950.

Although overall infant death rates (white and nonwhite combined) dropped from 26.0 in 1960 to 13.1 in 1979, very little change has occurred in the percent of very small babies born, the major factor contributing to infant deaths. In fact, Blacks in America, a so-called "developed" country, have such high rates of underweight babies that they have been used as a comparison group to populations in "developing" areas such as Argentina, Cuba, and Tanzania. In other words, nonwhites in America, one of the most affluent countries in in the world, exhibit the low birthweight patterns of residents of Third World countries.

In fact, national statistics demonstrate that there has been little change in the past 10 years in the percentage of infants who are born of low birth weight (that is, less than five 1/2 pounds). In 1972, the Black low birth weight rate was 13.3% of all Black live births; by 1980, the national Black rate was 12.5%. In major cities in the U.S., the rate was 13.08% in 1981. These trends confirm the widely held observation that the overall decrease in infant mortality in this country reflects improved medical care for high risk infants and not any significant decrease in the number of high risk infants born.

Small infants are not only at greatest risk of dying but, for those infants that live, and today the majority do, the mental and physical disabilities which they suffer and the expense of caring for them take an immeasurable toll on families, society, and the nation as a whole.

Civil rights, women's, children's, and health organizations have joined together in this Petition to ask the Reagan Administration to take those steps necessary to prevent low birth weight and resulting infant mortality. The organizations are deeply concerned that if action is not taken now, Black and other low income communities will be condemned to years of suffering from preventable infant deaths and morbidity.

This Administrative Petition not only proposes remedies to the problem, but provides new data from a survey undertaken by Public Advocates in conjunction with the University of California at Berkeley School of Public Health to determine the current status of maternal and infant health. Additionally, this Petition highlights the results of programs that have proven successful in increasing birth weight and lowering infant mortality. A cost effectiveness analysis of providing comprehensive prenatal care to those in need is also included.

The Public Advocates Survey is discussed in depth in Section IV. The most disturbing results are that infant mortality among Blacks is going up in a majority of the 45 cities surveyed and the low birth weight rates among Blacks have remained virtually unchanged. Further, the gap between white and Black infant death and low birth weight rates has dramatically widened.

Additionally, the Survey revealed that for those factors that contribute to low birth weight and infant mortality, the outlook is not good. Between 1978 to 1981, Blacks went from a teenage pregnancy rate 107% higher than whites to 118% higher. Regarding prenatal care, the Public Advocates Survey found that the percentages of Black and white women getting prenatal care in the first trimester had gone down while the percentages of women receiving no prenatal care had gone up.

There is no mystery concerning what is needed to increase birth weights and reduce infant mortality. For years the medical literature has been replete with references to the fact that early comprehensive prenatal care does increase birth weight and does decrease infant mortality. The programs reviewed in this document in Section V, further substantiate this premise. Not only is this information readily available in the medical literature, but the federal government has initiated several studies which have further documented that low birth weight is a serious public health problem in the United States and that identification of high-risk populations and the provision of comprehensive prenatal care to those groups can drastically reduce these appalling low birth weight and infant mortality rates. See Section VII.

Petitioning organizations reluctantly have included a cost effectiveness analysis which demonstrates conclusively that it would be cost effective for the federal government to embark on a national program to provide comprehensive prenatal care to low income women in need of this care. The reluctance to include the cost effectiveness analysis was not because there was any doubt that comprehensive prenatal care would prevent low birth weight and reduce the expenses that are necessarily involved in caring for those infants; but rather petitioners are so aware of the moral obligation to provide this most basic health care, that there should be no need to persuade the government that the provision of this care is cost effective. Cost effectiveness in this context seems callous and unnecessary.

Petitioners' analysis shows that the federal government can save $361,081,220 by providing comprehensive prenatal care to all low income women. See Cost Effectiveness, Section VI.

This cost savings figure was computed as follows: It currently costs the federal government $638,364,300 to pay for neonatal intensive care (NICU) and rehospitalization for low birth weight infants during the first year of life. This figure could be reduced to only $90,199,040 if comprehensive prenatal care were available to all low income women. The additional expense of providing such comprehensive prenatal care is $187,084,040. By subtracting the costs of the additional coverage ($187,084,040) from the projected savings of $548,165,260, a final cost savings figure of $361,081,220 is obtained.

Current federal cost for NICU and rehospitalization	$638,364,300
Federal cost after providing comprehensive prenatal care	- 90,199,040
	$548,165,260
Federal cost for providing comprehensive prenatal care	-187,084,040
Savings to federal government	$361,081,220

In general, America's low international ranking in terms of infant mortality is an embarrassment. A country with the wealth of the United States and the technological know-how should be at the top of the list of such a sensitive indicator of a nation's health. Actually, statistics indicate that the United States saves small babies on a par with any country in the world; the infant mortality rate in the U.S. remains high because there are so many small babies to save.

Recently, (May 24, 1983) the Wall Street Journal published an article describing how Sri Lanki had significantly reduced its infant mortality rate. Their efforts were described as a real success story for the Third World. The article discussed the reality that a country's infant mortality rate measures more than infant deaths but it is also a measure of "food and water supplies, political upheaval, and the quality of housing, schools, and health care." The writer went on state that the infant mortality rate also "measures. . . the attitude of the government." A Sri Lanka economist was quoted as saying that a high infant mortality rate "shows that the ruling elite aren't interested... It shows a high degree of irresponsibility." Similarly, something can be done about low birth weight and infant mortality rates in the U.S. Petitioners urge the Reagan Administration to take the responsible course and do something about it now.

In Section VIII, Petitioners put forward specific rule-making changes that can be implemented by Health and Human Services, which will coordinate existing federal programs aimed at maternal and infant care; develop an educational campaign that will inform women of the importance of prenatal care and make the need for prenatal care as well known to low income Americans as the Smokey the Bear campaign phrase, "Only you can prevent forest fires," is now known in every American home; encourage states to expand their Title V and Medicaid programs so that they can efficiently provide comprehensive prenatal care to all financially needy families, and begin to control the appalling problem of teenage pregnancy in America by providing pregnancy prevention information and prenatal care to high-risk teenagers if they become pregnant.

These solutions are interim steps. Legislative changes are clearly needed to permanently institutionalize this country's commitment to maternal and infant care. The rule-making changes proposed in this Petition, however, are important interim steps and will help prevent low birth weight and infant mortality.

Footnotes in this document are cross-referenced to the bibliography, where each reference has been assigned a number. Where a colon separates two numbers, the first number represents the document and the second number indicates the page. Where a semi-colon separates two numbers, it indicates more than one cite within the footnote.

II. PETITIONERS

This Petition is being filed on behalf of civil rights, women's, health and children's organizations that are concerned about the widening infant mortality gap between whites and nonwhites in the United States. These organizations are also deeply concerned that the failure to address adequately the underlying causes of infant mortality means that the gap will continue to widen until comprehensive prenatal care is available to all who need it.

A. Civil Rights Organizations

The National Urban League, the NAACP-Western Region, Mexican-American Legal Defense and Educational Fund, and the League of United Latin American Citizens are well known civil rights organizations with constituencies that range into the hundreds of thousands. These organizations believe that access to adequate health care is a fundamental civil right and that healthy pregnant women and babies are the cornerstone of a vital society.

B. Health Groups

The Black Women's Health Project (NWHN), National Women's Health Network, the Coalition for the Medical Rights of Women, the Coalition to Fight Infant Mortality, the Food Research Action Center and the Family Planning Forum focus on the particular health and nutrition needs of low income women and minorities. Each of these organizations devotes its resources to educating the public and encouraging policies that will make adequate health care available to all low income and minority citizens. These groups are gravely concerned that the high infant mortality rates in low income, minority communities persist when these rates could be reduced if health resources were properly directed to the populations most at risk.

C. Women's Organizations

The National Organization for Women Legal Defense and Educational Fund and the National Council of Negro Women recognize women's needs for adequate health care as well as their need for opportunities in education, employment and personal advancement. Of key concern is that pregnant women have the necessary resources and support to bring healthy, potentially productive babies into the world. This cannot be accomplished if the low income and minority women in this country are denied access to the quality of health care that is available to middle and upper income women.

D. Children's Organizations

The National Black Child Development Institute is a non-profit membership organization with affiliates in 32 cities which plays an advocacy role for all Black children. It has focused on such issues as adoptions, foster care, and education.

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III. JURISDICTION AND RESPONDENTS

The cabinet and sub-cabinet members of the Department of Health and Human Services have the authority and power to promote policies, programs and practices which will reduce infant mortality among the nation's high-risk populations.

Respondent Secretary of Health and Human Services (DHHS)

Secretary Heckler is vested with the authority to guide the nation's health policies and the power to implement existing federal health legislation, 42 U.S.C. § 3501. Specifically, the Secretary is entitled to receive reasonable assurances that certain conditions will be met prior to the disbursement of federal grants for health care pursuant to the Maternal and Child Health Program (Title V of the Social Security Act, 42 U.S.C. § 701, et seq.), the Adolescent Pregnancy Programs (Title VI of the 1978 Amendments to the Public Health Service Act, 42 U.S.C. § 300 et seq.), the Comprehensive Public Health Service Grants Program (42 U.S.C. § 246), Migrant Health Centers and Services Grant Program (42 U.S.C. § 254b), Community Health Centers (42 U.S.C. § 254c), the Family Planning Services and Population Research Act (Title X of the Public Health Service Act 42 U.S.C. § 300), and the Social Services Block Grant Title XX (42 U.S.C. § 1397a(a)(2)(A)).

Further, under the Social Security Act, which encompasses both the Maternal and Child Health Program and Medicaid, the Secretary is given broad authority to mandate "such rules and regulations, not inconsistent with this chapter, as may be necessary to the efficient administration of the functions with which (s/he) is charged under this chapter." 42 U.S.C. § 1302. The Medicaid program specifically provides in pertinent part that: "A state plan for medical assistance must provide such methods of administration. . . as are found by the Secretary to be necessary for the proper and efficient operation of the plan." 42 U.S.C. § 1396a(a)(4).

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IV. EVERY SIGNIFICANT INDICATOR REVEALS A WIDENING GAP BETWEEN THE SURVIVAL PROSPECTS OF BLACK AND WHITE INFANTS

The overall infant mortality rate is a crude, imprecise measure of a nation's health. Recently, increases in the overall rate in 11 states have touched off heated exchanges between government critics and bureaucrats about who is responsible.[1] The death of American babies is an issue that deserves open and pointed debate; while the debate rages, however, babies are dying needlessly.

Hidden under the overall infant mortality statistics are truly shocking figures that no one--including government officials--disputes: in America today, a Black baby is almost twice as likely as a white baby to die before his or her first birthday.[2]

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[1] 107:7

[2] 11:7

The following is an in depth discussion of infant mortality in the United States which both compares this country's ranking with other countries and examines infant mortality among various groups within the U.S. This section also reports the methodology and results of a survey conducted by Public Advocates. This survey was undertaken because of the lack of current data regarding infant mortality rates by race. The Public Advocates survey was conducted in conjunction with the University of California at Berkeley School of Public Health.

A. Public Advocates' Survey

1. Lack of Current Data

The last year for which final state and national infant mortality statistics are available from the National Center for Health Statistics (NCHS) is 1979.[1]* Currently, there is almost a three-year lag between the end of a calendar year and the date on which final statistics for that year are released to the public by NCHS. Provisional statistics (based on a 10%

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[1] 102:24

* On June 30, 1983, one day after this Petition was filed, Dr. Edward Brandt, Assistant Secretary for Health, and attorneys for petitioners both testified before Congress' Select Committee on Youth, Families and Children. Dr. Brandt made public for the first time the final 1980 statistics, which were an overall IMR of 12.6, a Black IMR of 21.4, and a white IMR of 11.0.

sample of the population) are available for 1980, 1981, and 1982 but racial breakdowns for infant deaths have not yet been published for these years.

Breakdowns of city data needed for analysis in this petition have not been available from the federal government or government-sponsored sources since 1978.[1]

Public Advocates reviewed the state and national statistics from NCHS, including provisional data for 1980-1982 and natality data for 1980, but also conducted an additional survey to collect more recent data for selected cities throughout the country.

2. Methodology

During the first half of 1983, Public Advocates conducted a telephone survey and collected data on infant mortality broken down by ethnicity or race from 45 cities. These cities varied in their racial, ethnic and socio-economic makeup: 30 cities had populations of 250,000 or more, 15 had populations below 250,000. Geographically, 7 cities were located in the East and Northeast, 12 in the Midwest, 13 in the South and Southeast and 13 in the West. Where city data was not available, county statistics were used.

Most of the cities were randomly chosen. A few cities, however, were selected for study because community groups alerted

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1. 114

Public Advocates to their high rates of infant mortality; other cities were selected because the media had already focused attention on their high rates of infant deaths.

For the 45 cities information was requested from vital statistics divisions of city, county and state health departments for the years 1978 through 1982 for the following categories: overall infant mortality rate (IMR),[a] IMR by area of city, stillbirths,[b] neonatal deaths,[c] post-neonatal death rate,[d] low birthweight,[e] prematurity,[f] teenage pregnancies, and prenatal care. Breakdowns by race were requested for each category. All data collected was for city residents.

Inconsistencies in recordkeeping and lack of data collection by race in the cities' vital statistics units prevented Public Advocates from obtaining data for every category from each city. Few cities had compiled data for 1982. Infant mortality and low birth weight statistics were most consistently available. Small samples were obtained for very low birth weight births, births to teenagers, and prenatal care. Also a few cities reported nonwhite rates rather than Black rates. In the Public Advocates Survey (hereinafter sometimes referred to as P.A. Survey) Black and nonwhite were combined. Most references to the PA survey will refer to those rates as Black.

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a. infant deaths per 1,000 live births
b. fetal deaths, excluding abortions
c. deaths to infants under 28 days old
d. deaths to infants 28 days to one year old
e. less than 5 1/2 pounds (2,500 grams) at birth
f. born before 38 weeks' gestation

The data were subsequently processed and analyzed by Consultants from the School of Public Health, University of California, Berkeley.

The findings of the Public Advocates Survey appear throughout this petition.

B. Infant Mortality Rate (IMR) - Components and Significance

The infant mortality rate (IMR) is the number of infant deaths up to one year of age, per 1,000 live births. For example, if a country had 3,000 live births in a given year and 33 infants under age one died in the same year, that country's IMR would be 11.0 (33 divided by 3,000, multiplied by 1,000).[1]

IMRs can be based on linked data (where birth and death records are matched for each individual infant) or on unlinked data (all births and deaths occurring in a calendar year). Most of the statistics in this petition are based on unlinked data. Linking is not routinely done in the United States, except for a few states and cities.[2]

Although crude IMRs can provide some clues to the status of a nation's health, especially the health of mothers and babies, the statistics which comprise overall IMRs--i.e., death rates before and after the first 28 days of life--are often more sensitive measures of national health and of specific remedial

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1. 75:1
2. 83:15-16; 115

and preventive techniques which affect that health.

Similarly, more insight can be gained by comparing IMRs for various subpopulations: whites to nonwhites, babies whose mothers had prenatal care to those who did not, teenage mothers to older mothers, pregnant women above the poverty level to those below it, and babies who are born underweight to those of normal weight.

In reviewing the professional literature, as well as in its own survey, Public Advocates focused on data that would shed light on this complex interaction among these factors and how they affect crude, overall IMRs.

1. Neonatal Mortality (deaths occurring within the first 28 days of life)

There is an especially strong link between high neonatal deaths and babies born underweight (or low birthweight). The neonatal death rates for babies who weigh 1,000 grams or less is 750 per 1,000 births, as compared to only two deaths per thousand for babies who weigh between 3,000-3,500 grams.[1]

Fifty years ago, a little more than half of infant deaths in America occurred in the neonatal period,[2] the first 27 days of life. Now, three-fourths of all infant deaths occur in the neonatal period.[3] This shift does not mean that more babies are dying now than in previous years. Fewer are dying. The percentage of deaths in early infancy is rising

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1. 147:829
2. 147:829
3. 50

because of advances in the past half-century in controlling the factors -- e.g., poor sanitation, infection -- which killed babies later in infancy.[1]

Neonatal deaths are closely linked to inadequate prenatal care, delivery procedures, and medical care of the newborn.[2] The neonatal period is also the time when intrauterine factors, such as retarded fetal growth, have their greatest effect.[3]

Race is also a factor. In 1979, the Black neonatal death rate was 80% higher than the white rate.[4]

2. Post-Neonatal Mortality (deaths occurring from 28 days up to one year)

Post-neonatal deaths account for only one-fourth of infant deaths in the United States.[5]

Environmental, social, and economic factors, e.g., poverty, are more likely to affect infants after the first month of life.[6] Much of post-neonatal mortality is not related to, nor influenced by, prenatal care.[7] Further, there is disturbing evidence that in some cases, medical science is prolonging the lives of tiny infants who are born critically ill and do not survive. In the U.S. between 1970-1978, the numbers of infant deaths related to respiratory disease, one of the three major complications of low birthweight that often leads to death, decreased

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1. 50:3
2. 104:8
3. 125:366
4. 104:8
5. 50:4
6. 104:8
7. 55:6

overall by 31% but increased 444% in the postneonatal period.[1]

In 1979, the last year for which final national data are available, the Black post-neonatal death rate was more than twice the white rate.[2]

3. Fetal Mortality - Stillbirths

Fetal deaths (stillbirths) include deaths of fetuses of 20 or more weeks' gestation, excluding abortions.

Historically, nonwhite fetal death rates have been higher than the white rate. In 1950, the nonwhite fetal mortality rate* (FMR) was 24.8; the white FMR was 13.3. ("Nonwhite" includes Blacks; fetal death rates for Blacks-only were not available until 1979.) By 1970, the white rate was down to 8.6, while the nonwhite rate was 13.9. The gap between white and nonwhite fetal deaths rates had narrowed by 1979 (5.9 for whites and 8.4 for nonwhites). Unfortunately, the newly available 1979 rate for Blacks-only was 9.0 higher than the nonwhite rate, and white rates. Provisional 1980 fetal mortality rates by race are not yet available from NCHS.[3] Some cities include fetal deaths when reporting infant mortality rates, but in the Public Advocates Survey, all fetal deaths were excluded.

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[1] 27:70

[2] 104:8

[3] 104:54

* Fetal mortality rates (FMRs) are the number of fetal deaths divided by the total live births plus fetal deaths, multiplied by 1,000.

4. International Comparisons of Infant Mortality

The overall infant mortality rate, although a crude measure by American standards, is nonetheless useful in international comparisons. For the past 17 years, the U.S. has maintained the unimpressive rank of between 14th and 18th of 25 industrialized nations with the lowest infant mortality rates.[1] For many years, the U.S. infant death rate has exceeded Sweden's by more than 75%.[2] In 1974, when the U.S. rate was 16.7, Sweden's was 9.2.[3]

In 1978, America's infant death rate (13.8) was higher than the IMRs for fifteen other nations, not an enviable record for a country with a high standard of living. In the past 50 years, the infant death rate for Finland and Japan declined more than 90%, while the U.S. rate dropped only 80%.[4]

America's international ranking fell from sixteenth in 1978 to eighteenth in 1979. Among the countries with lower infant death rates than the U.S. were: Sweden (7.3), Canada (10.9), Hong Kong (12.3), Australia (11.4), and West Germany (12.9). The U.S. ranked only six countries above Czechoslovakia (17.7).[5]

In 1980, the U.S. was still ranked eighteenth worldwide, with an infant death rate of 12.5 per 1,000 live births.

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[1] 64:986
[2] 64:986
[3] 146:213
[4] 147:832
[5] 147:761

America's IMR was barely better than East Germany's (12.6), and was worse than seventeen other countries, including Sweden (6.9), Japan (7.5), Finland (7.6), Spain (11.1), Hong Kong (11.2) and Ireland (11.2).[1]

To appreciate the lifesaving impact of an infant death rate which is approximately five points lower consider the following: If the U.S. infant death rate in 1977, which was 14.1, had been equal to Japan's (8.9), 17,000 fewer American babies would have died that year.[2]

Despite the historical and present lag, the most optimistic goal thus far proposed by the U.S. Department of Health and Human Services is to lower the national infant death rate to no more than 9.0 per thousand (slightly higher than Japan's 1977 rate) by 1990. The more conservative 1990 goal for Blacks, Hispanics, American Indians, and other ethnic subgroups (12.0 deaths per thousand live births) institutionalizes rather than eliminates the current racial death gap.[3]

Countries with lower rates of infant mortality than the United States use comprehensive preventive programs which stress adequate and accessible prenatal care, sex education for teenagers, good nutrition, screening for high-risk pregnancies, high quality obstetric care, and follow-up home visits, plus other basic preventive services.[4] These services have yet to

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1. 148:842
2. 147:842
3. 139:17
4. 146:217; 64:985; 128:28

become the right of every mother and baby in the United States, making even the modest 1990 goals seem impossible to reach.

5. U.S. Infant Mortality Rates by Race

> "Higher mortality among black infants has been observed ever since reliable statistics have been available. Furthermore, the gap is not narrowing..."
>
> Joel C. Kleinman, Ph.D.
> Samuel S. Kessel, M.D.
> National Center for Health Statistics[1]

Between 1915 and 1950, there was a steady decline in the U.S. infant death rate, largely due to better sanitation, decreases in infectious diseases, family planning, improved nutrition, and better access to health care.[2]

As shown in Table A, by 1950, the U.S. infant mortality rate for whites was 26.8 deaths per 1,000 live births. Black American infants, however, died at a rate 64% higher (43.9 deaths per 1,000 live births). Twenty years later, in 1970, the white IMR was down to 17.8, while the Black IMR (32.6) was 83% higher than the white rate. In 1979, the last year for which racial breakdowns are available from the National Center for Health Statistics, the white rate reached an all-time low of 11.4. Again, the Black rate, consistent with this deplorable statistical pattern, was 91% higher (21.8).[3] The gap is indeed widening.

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1. 76:29
2. 50:3
3. 104:54

TABLE A

U.S. Infant Mortality Rates, 1950-1981 (selected years), By Race (per 1,000 Live Births)

Year	U.S. Overall	White IMR	Black IMR
1950*	29.2	26.8	43.9
1970	20.0	17.8	32.6
1975	16.1	14.2	26.6
1978	13.8	12.0	23.1
1979	13.1	11.4	21.8
1980	12.5**	***	***
1981	11.7**	***	***

Sources: National Center for Health Statistics, "NCHS Monthly Vital Statistics Report," V. 30, N.13, 12/20/83. Health U.S., 1982, p. 54.

The provisional 1982 overall U.S. IMR is 11.2 per 1,000 live births, the lowest rate ever recorded in the United States. That is little comfort for Black parents, since "the mortality rate for Black infants remains almost twice as high as that for white infants."[1]

It is difficult to obtain accurate data on infant deaths in the Hispanic community.[2] Statistics are also sparse for other ethnic groups. In Los Angeles County, however, several areas with the highest minority concentrations also have the highest rates of underweight babies, neonatal deaths, and infant deaths.[3]One Los Angeles County health planning area,

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1. 11:7
2. 87
3. 87, see appendix

* Includes nonresidents of U.S.
** Provisional statistics.
*** No racial breakdown available.

where Hispanics make up 58.9% of the population, has the highest percentage of underweight babies and the fifth highest infant death rate in the County.[1]

IMRs for American Indians living in the State of California are higher than the IMRs for any other reported group except Blacks.[2]

- Public Advocates Findings - Infant Mortality by Race

The Public Advocates findings from the survey of cities were consistent with though not identical to the national figures from NCHS for the duplicate years studied (1978-79). As in the NCHS report, Public Advocates' Survey revealed an increase in the gap between the white and Black IMRs. The Survey included infant mortality rates by race for 45 cities. The total number of births is in excess of 376,000 for whites and 227,000 for Blacks per year. For those cities in 1978 the white IMR was 12.9 while the Black IMR was 21.9, a rate 70% higher than that for whites. By 1981, the rate for whites had fallen significantly to 11.58 while the Black IMR had decreased only slightly and was actually higher than the 1980 rate. Thus, at the end of 1981, the IMR for Blacks was 82% higher than the IMR for whites.

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[1] 88

[2] 25:23

TABLE B[*]

Public Advocates Survey of IMR of 45 Cities

Year	White IMR	Black IMR	% Higher for Blacks than Whites
1978	12.86	21.93	70%
1979	12.36	21.27	71%
1980	12.62	20.25	73%
1981	11.58	21.13	82%

Further, the Public Advocates survey revealed that in 32 of the 45 cities, the Black infant mortality rate for 1981 was more than 50% greater than the white rate. Fifteen of those had Black rates that were more than double the white rate.

According to the Public Advocates survey, in 1981, among the larger birth populations, the widest disparities in IMRs between whites and Blacks occurred in the following cities: Jackson, Mississippi; Memphis, Tennessee; Cleveland, Ohio; Washington, D.C.; and Detroit, Michigan. Jackson, for example, showed IMRs of 6.2 and 21.1 for whites and Blacks respectively; these data indicate that the Black IMR was 240% higher than the IMR for whites. See Table C.

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[*] All averages reported in P.A. findings are weighted to eliminate the impact of varying city sizes. A weighted average is computed by using total number of births and total number of outcomes.

TABLE C

Public Advocates Survey of Cities with Number of Black Births Greater than 2,800 in 1981 with Widest Disparities Between White and Black IMRs

CITY	WHITE IMR	BLACK IMR	% HIGHER FOR BLACKS THAN WHITES
Jackson	6.2	21.1	240%
Memphis	7.9	22.6	186%
Cleveland	11.5	31.9	177%
Washington, D.C.	9.5	25.3	166%
Detroit	12.0	26.2	118%

Perhaps the most disturbing evidence indicated by the survey is that infant mortality among Blacks and whites is rising. Between 1980 and 1981 the PA Survey found increases in the Black IMRs in 51% of the cities studied. The white populations in these cities are not immune to the high incidence of infant deaths; increases in white IMRs were found in 37% of the cities studied for those same years.

Probably the rise in white IMRs is influenced by the same factors that are contributing to a rise among Blacks; that is, higher IMRs among people who are low income. A comparison of the national IMR for whites for 1978-79 with the results of the Public Advocates Survey indicates that IMRs for whites in the survey cities were higher than the national average.

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TABLE D

National Comparison of White IMR to Public Advocates Survey for 1978-79

Year	National	Public Advocates Survey
1978	12.0	12.86
1979	11.4	12.36

This may reflect the fact that cities often contain small concentrations of low income whites.

While it may be premature to conclude from these data that the infant mortality rates for poor whites and Blacks are increasing, a pattern in that direction seems to be developing. While more data from 1982 and 1983 is needed to determine whether that trend is in fact occurring, it may fairly be said that a significant problem may be emerging -- one which may be difficlt to combat if not treated immediately.

C. Low Birth Weight, Death, and Disability

> "Low birth weight is the greatest single hazard for infants, increasing their vulnerability to developmental problems and to death." U.S. Surgeon General's report".[1]

There are two reasons for an infant to be of low birth weight (i.e., born weighing less than 5 1/2 pounds or 2,500 grams).

1. It was born too soon (prematurity -- before 38 weeks

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[1] 136:21

gestation), or

2. It was born too small. These are full-term babies who did not grow enough while inside the mother [intrauterine growth retardation (IUGR)]. They are also referred to as "small for gestational age" (SGA).[1]

In either case, low birth weight infants are more likely to die or have serious disabilities than normal birth weight (NBW) babies (5 1/2 pounds or more).[2] In both types of LBW, the lower the birth weight, the more likely the baby will be stillborn or die soon after birth.[3] Low birth weight (LBW) infants are more than 20 times as likely to die within their first year as normal birth weight babies.[4]

Figure 1 illustrates the strong relationship between low birth weight and death, especially in early infancy.

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[1] 81:3-4, 50:1

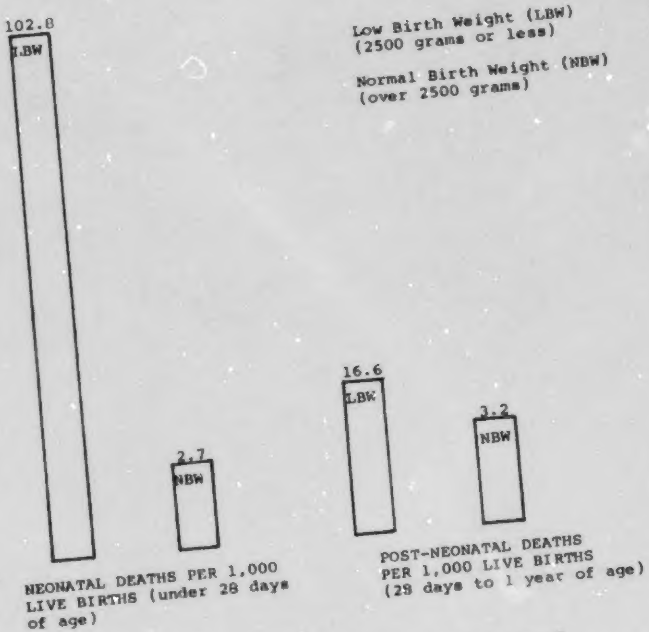
[2] 50:1

[3] 81:3

[4] 136:24

Figure 1

NEONATAL AND POST-NEONATAL DEATHS, ACCORDING TO BIRTHWEIGHT, 1974-75 -- Selected Areas, United States



Source: Shapiro, S., et al., "Relevance of Correlates of Deaths for Significant Morbidity at 1 Year of Age", Am.J. of Obstet. Cynecol., Feb. 1, 1980, p. 365, Table II.

LBW has also been connected with increased occurrence of mental retardation, learning disabilities, birth defects, blindness, autism, cerebral palsy, epilepsy,[1] growth problems, visual and hearing defects, delayed speech, and chronic lung problems.[2]

In the first large-scale study of morbidity by birthweight, which covered eight regions in the U.S., researchers at Johns Hopkins University found that, among infants with birthweights below 1500 grams born in the first half of 1976, the incidence of severe impairment was 14.3 percent.[3] The authors also compared overall problems of low-birthweight infants to those suffered by full-term babies and found that 40 percent of the survivors born under 1500 grams were hospitalized at least once during the first year of life, compared to 8 percent of infants born weighing over 2500 grams.[4]

Continuing physical problems are common in very low birth weight (VLBW) infants -- those weighing under 3 lbs., 5 oz., or 1500 grams. By the time they reach one to three years of age, 20 percent of VLBW infants and 30 percent of those weighing under 2 lbs., 3 oz. (1000 grams) have neurological abnormalities.[5]

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1. 136:24
2. 50:2
3. 113
4. 136
5. 136

1. International Comparison of LBW Rates

International data comparing the U.S. to nine other industrialized nations rank the U.S. second worst in proportion of LBW babies.[1] This high percentage of underweight babies, a percentage which is even higher among America's racial minorities, is one reason for the poor U.S. ranking in infant deaths.[2]

In 1970, only 4.5% of babies born in Sweden (the country with the lowest IMR in the world) were LBW, while 7.8% of U.S. babies were LBW.[3] In 1978, eight years later, the U.S. LBW rate* had only inched down to 7.0%, still far above the Swedish rate.[4]

As an indication of the lifesaving potential of improving LBW percentages, when researchers compared infant and neonatal death rates for each weight category (*e.g.*, 1500-2000 grams, 2000-2500 grams) rather than for all LBW categories combined, they found that babies of the same weight, on the average, had lower death rates in the U.S. than in Norway and Sweden.[5]

This result indicates that the United States saves LBW babies on a par with other countries. What is also obvious is that this country is not as good at preventing low birth weight. America's international rank is not expected to improve until

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1. 50:3
2. 104:8
3. 146:213
4. 139:15
5. 47:990; 61:1232

* The percentage of babies per hundred live births, who weigh less than 5 1/2 pounds at birth.

the low birth weight rate is reduced.[1]

One observer of the Swedish health care system states that ". . . a compelling case can be made for some solid efforts to emulate the comprehensiveness of Swedish prenatal care and education . . ."[2] Sweden has put a high priority on making sure that its babies are born healthy, one reason for its enviable top world ranking. Swedish mothers are well educated about the value of prenatal care, receive free prenatal care, which includes screening for high-risk patients, and free vitamin and mineral supplements.[3]

As Hein acknowledged, the United States is comparable with Sweden medically, economically, and technologically. "Perhaps it is time for us to find reasonable solutions for our perinatal problems rather than acceptable excuses."[4]

2. Factors which Influence Birthweight

Factors linked to higher risks of low birth weight are: race (not white), age of mother (less than 18 or greater than 35), previous loss of a fetus or infant, short interval between pregnancies, out-of-wedlock birth, no prenatal care,[5] educational attainment of mother (risk decreases as educational status increases), maternal smoking and consumption of alcohol, poor maternal nutrition, poverty,[6] gestational age,[7] and

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1. 47:990
2. 110:1028
3. 146:217
4. 64:986
5. 125:367-368
6. 50:4
7. 72:7

weight gain of the pregnant women.[1]

It is difficult to say that any one of these factors directly causes LBW in babies, and consequently, higher infant death rates. Not every malnourished mother has a low birth weight baby. Not every Black mother has a low birth weight baby. Not every mother who has no prenatal care has a low birth weight baby. But, statistically, where one or more of these factors is present, the likelihood of low birth weight increases.

3. Race and Low Birth Weight

Race is closely associated with low birth weight. A greater proportion of nonwhite infants than white infants weigh less than 5 1/2 pounds at birth.[2] Black infants are about two and one-half times as likely as white infants to be of very low birth weight (under 1500 grams) and two times as likely to be of low birth weight (under 2500 grams).[3]In one classic study of New York births, differences in birthweight accounted for virtually the entire excess of the perinatal death rate of non-whites over that of whites (an excess of 69%).[4]

Nationwide between 1972 and 1974, the Black low birth weight rate (13.3%) was 107% higher than the white LBW rate (6.4%).[5] In 1980 whites gave birth to underweight babies at a rate of

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1. 72:21
2. 105:3
3. 77:12
4. 7:946
5. 103:75

5.7. For the same year, the rate for Blacks was 12.5. Thus, the Black low birth weight rate climbed to 119% higher than the white rate.[1]

Figures from the Los Angeles County Health Systems Agency show that planning areas with the highest concentrations of minorities also have the highest LBW rates, neonatal death rates, and infant death rates.[2]

- Public Advocates Findings - Race and Low Birthweight

Public Advocates collected low birth weight data from 32 cities by race for the years 1978-81. Data from 1982-83 would be useful in determining a clear pattern. From the data available, however, it is apparent that there has been no decrease in the incidence of low birth weight particularly among Black infants.

Like the IMR statistics, the data collected in the Public Advocates Survey reveal that the Black low birth weight rate (LBWR) is nearly double the white rate.

TABLE D

Public Advocates Survey of LBWR of 32 Cities *

Year	White LBWR	BLACK LBWR	% Higher for Blacks than Whites
1978	6.7	13.03	94%
1979	6.8	13.13	94%
1980	6.7	12.78	90%
1981	6.8	13.08	92%

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[1] 102:24
[2] 87:9
* For list of 32 cities see single asterisk cities in Appendix.

It is disturbing to note that while the white LBWRs remained fairly constant, the gap between whites and Blacks widened in 1981 after narrowing from 1979 to 1980.

Cities that experienced wide disparities in the IMRs between Blacks and whites tended to also show large differences in LBWRs. These included: Washington, D.C., Cleveland, Memphis and Detroit. A complete comparison is not possible because many cities that provided IMR data could not produce LBWR data broken down by race.

It is interesting to note that of the 32 cities studied, 47% showed increases in the incidence of low birth weight of Blacks from 1980-81. This again may be the beginning of a trend that could have serious implications for future infant mortality and morbidity.

The most disturbing data uncovered by the Public Advocates survey were the percentages of very low birth weight (VLBW) babies, those born weighing between 500 to 1500 grams (or approximately 1 pound and .6 ounces to 3 pounds and 4 ounces). These findings are displayed in Table E below.

TABLE E

Public Advocates Survey of VLBW Rates for 7 Cities*

YEAR	WHITE % VLBW	BLACK % VLBW	%HIGHER FOR BLACKS THAN WHITES
1979	1.3%	2.5%	86%

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* For list of 7 cities see double asterisk cities in Appendix.

(Table E Continued)

1980	1.2%	2.47%	105%
1981	1.17%	2.72%	132%

Data for 1978 were excluded due to an extremely small sample; data for 1979, 1980 and 1981 were based on 7 cities. Comparisons of years are useful even though only a small number of cities was studied. The data show that whites experienced a decline in the number of VLBW infants while their Black counterparts experienced an increase. Moreover, the gap between Blacks and whites seems to be rising at an accelerated pace. In 1979, Black women gave birth to VLBW babies at a rate that was 92% higher than that for white women. By 1981, that rate had increased to 132%. That means that the gap increased almost 50% within a span of only three years.

This trend is particularly disturbing because VLBW babies are the ones that pose the most serious risk of death. They also require the greatest expense due to a high likelihood of rehospitalization and future medical problems. It is discouraging to report that rather than observing improvements for these high risk infants, the record shows movement backwards.

4. Lack of Prenatal Care and Low Birth Weight

The chances of having a low birthweight baby are three times as great when an expectant mother receives no prenatal care.[1]

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[1] 136:24

The chances for low birth weight--and perhaps death-are also greater than normal if the prenatal care is not early, regular, and of high quality.[1]

In one study, infant death rates went up as the number of prenatal visits went down.[2] Another study concluded that infants born to women who had five or fewer prenatal visits had five times the neonatal mortality (under 28 days) of infants born to women who had six or more visits.[3]

Although Black mothers are more likely to have low birth-weight babies, they are less likely than white mothers to get early prenatal care (Table F). In 1978, one-fourth of all pregnant American women did not receive prenatal care in the crucial first three months (first trimester) of pregnancy. One-fifth of these women began prenatal care in the last (third) trimester, or received no prenatal care. Predictably, twice as many Black mothers (9.3%) as white mothers (4.5%) were in this last category of very late or no prenatal care.[4]

In 1990, 77.3% of white women received prenatal care in the first trimester as compared to 60.4% of Black women.

Racial disparities in low birth weight rates occur even among babies whose mothers receive no prenatal care. A study of 35,871 U.S. babies found that the low birth weight rate was

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[1] 136:86
[2] 43:858
[3] 55:6-7
[4] 104:77

15.3% among white mothers who had no prenatal care. The low birth rate for Black babies whose mothers had no prenatal care was 25.7%, or 68% higher.[1]

Table F below shows the national patterns of prenatal care for selected years 1970-1980. Consistent with other data presented, Black women are twice as likely as white women to receive poor prenatal care.

TABLE F

TRIMESTER PRENATAL CARE BEGAN, BY RACE,
1970, 1974, 1978 and 1980 -- UNITED STATES

Prenatal Care Began	1970	1974	1978	1980[2]
First Trimester (first three months):				
Black	44.4%	53.9%	60.2%	60.4%
White	72.4%	75.9%	78.2%	77.3%
Third Trimester (last three months) or No Prenatal Care:				
Black	16.6%	11.4%	9.3%	8.5%
White	6.2%	5.1%	4.5%	4.1%

Source: DHHS, *Health, United States, 1982*, p. 77, Table 24.

• Public Advocates Findings - Prenatal Care

Public Advocates attempted to collect data on prenatal care from all of the cities for which IMR data were collected. Statistics on prenatal care broken down by ethnicity and race, however, were found in only 6 cities. Thus, conclusions based on these findings may not be definitive. Nonetheless, a review of these findings does reveal certain patterns.

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[1] 46:890
[2] 103:22

For the six cities reporting prenatal care by race, there was a slight decrease for 1978 to 1981 in the percent of Black and white women receiving first trimester prenatal care. For the same period, there was also a slight increase in the percent of women receiving no prenatal care. See Table G, below:

TABLE G

First Trimester Care For 6 Cities *

YEAR	WHITE	BLACK
1978	78.3%	62.8%
1981	74.7%	61.0%
No Care	White	Black
1978	1.34%	2.58%
1981	1.39%	2.67%

Again, these data, based on a smaller than desirable sample are not conclusive; but they do indicate that a pattern might be developing, a pattern that would have a detrimental impact on America's health.

5. Teenagers and Low Birth Weight

Babies born to teenage mothers are more likely to be of low birth weight,[1] and to die in their first year of life[2] than

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1. 136:25
2. 60:28

* For list of 6 cities see quadruple asterisk cities in Appendix.

babies born to mothers over age 20. Mothers aged 15 and younger are twice as likely to have low birth weight babies as are mothers aged 20 to 24. Even mothers aged 19 have LBW rates 27% higher than those who wait until their early twenties.[1]

Black mothers are more likely than white mothers to give birth before age 18,[2] and almost 8 times more likely to be under age 15,[3] which means that Black mothers have more births at an age which correlates with the highest percentage of LBW babies.[4] Black teenagers are also more likely than white teenagers to have a LBW baby.[5]

The high incidence of LBW babies among teenage mothers may be due to the "double disadvantage" of being immature physically and living at or near the poverty level. Families headed by young mothers are seven times more likely to be living below the poverty level than other families.[6] In 1975, $4.7 billion in federal welfare payments went to support mothers who had given birth as teenagers.[7] A higher percentage of Black infants than white infants are born to unmarried teenagers, which also increases the incidence of LBW.[8]

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1. 60:29
2. 46:889
3. 50:4
4. 46:889
5. 60:29
6. 60:33
7. 60:32
8. 77:10

The lower birth weights of babies born to teenage mothers contributes to higher neonatal (under 28 days) mortality rates, (NMR). Babies weighing 5 1/2 lbs. or less (LBW) born to teenage mothers had a NMR of 111.4 per 1,000 live births, while the NMR was only 2.4 per 1,000 live births where the infant weighed more than 5 1/2 lbs.[1]

a. Teenage pregnancies -- statistics

In 1978, there were over one million teenage pregnancies.[2] Seventy-four percent (847,000) were unintended[3] and almost 40 percent (434,000) ended in abortion.[4] More than one out of every 10 teenage women gets pregnant each year, and the proportion is rising.[5] In 1978, teenagers were responsible for almost one-sixth of all live births in the United States.[6]

In the mid-to-late 1970s, the United States teenage birth rate was higher than the rates for 29 other countries, including Singapore, Malaysia, Tunisia, and the Philippines. The U.S. rate is more than three times the rate for the Soviet Union, and about the same as the rate for Italy and Thailand.[7]

b. Teenage pregnancies -- outlook

Despite the enormity of the problem of teenage pregnancies in America, only four out of every 10 teenagers receive information about reproduction in the schools; only three out of 10 teenagers learn about contraception.[1] The Select Panel for the Promotion of Child Health found that although the proportion of 15 to 19 year-old women who had engaged in premarital sex increased from 30% to 50% (1971-1979), more than one-quarter of these teenagers had never used contraceptives, and close to two-thirds of this group became pregnant.[2]

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[1] 125:366-367
[2] 60:17
[3] 60:20
[4] 60:17
[5] 60:4
[6] 147:824
[7] 60:23

Once a teenager becomes pregnant, she is less likely than other pregnant women to get the early, high-quality prenatal care which could avert many of the damaging health consequences of early childbirth. Mothers under age 15 are 2 1/2 times more likely than mothers age 20-24 to get no prenatal care in the first trimester (first three months) of pregnancy, and nearly four times as likely not to get any care or to delay care until the last trimester. Mothers 15 - 17 are twice as likely as those age 20-24 to get no care in the first trimester and to have no prenatal care or none until the last trimester.[3]

Public Advocates' Findings - Teen Pregnancy

The Survey revealed that for the 13 cities reporting teenage pregnancy data by race, the incidence of teenage pregnancy is falling for both whites and Blacks. While these figures may seem encouraging, the raw figures are not. In 1981, the year for which the survey population showed the lowest percentage of teenage pregnancies, the Survey revealed

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1. 60:20
2. 138:30
3. 60:59

160

that 26,505 babies were born to Black mothers between the ages of 15-19. In contrast, 11,452 babies were born to white mothers in the same age group.

In addition, the disparity between Black and white teenage pregnancy rates seem to be increasing. In 1978, the Black rate was 107% higher than the white rate of teen pregnancy. After falling to 100% in 1980, the gap increased in 1981 to 118% higher among Blacks than whites. These figures are shown in Table H below.

TABLE H

Teenage Pregnancy: Mothers Age 15-19 For 13 Cities*

YEAR	% WHITE TEEN PREGNANCY	% BLACK TEEN PREGNANCY	%HIGHER FOR BLACKS THAN WHITES
1978	13%	27%	107%
1979	12%	26%	116%
1980	13%	26%	100%
1981	11%	24%	118%

Perhaps the most troubling data analyzed in the area of teen pregnancies is that for mothers under the age of 15. Though a decrease may be detected for whites and Blacks in this age group, the incidence of teenage pregnancy for Blacks (in 1979) was 11 times higher than for whites. In 1980, the Black rate decreased to 4 times the rate of whites but increased to six times the white rate in 1981. As in the data for teens in the higher age group, these raw figures reveal the startling dimensions of the teenage pregnancy problem. In 1981, for the

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* For list of 13 cities see triple asterisk cities in Appendix.

13 cities studied, while 122 white mothers under the age of 15 gave birth to babies, 1,021 Black mothers in the same age group gave birth. The outlook for these young mothers, who have not completed their education and who are without means of financial security, is not promising.

6. Poverty and Low Birth Weight

There is a clear relationship between poverty and low birth weight babies,[1] and between poverty and higher risk of infant death.[2]

Infant death rates in 50 states and the District of Columbia were found to be higher in areas where a higher percentage of the population lived below the poverty level.[3] In Michigan, a state which from 1980 to 1981 experienced one of the greatest yearly increases in infant deaths since World War II, the Department of Health concluded that the rise in IMRs was consistent with poor economic conditions, high unemployment rates, and unprecedented cutbacks in social services.[4] "The poor, irrespective of race, experience a higher low birth weight rate because of the interactive effects of poor housing, diet, medical care and related factors."[5]

Many of the factors which are linked to low birth weight--

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1. 136:25
2. 43:858
3. 52a:29
4. 97:8
5 97:9

poor maternal nutrition, low educational level, race nonwhite, teenage pregnancies, and unwed mothers--are more predominant in poorer communities. "Put simply, poorer mothers have smaller babies, and smaller babies are at higher risk of early death."1

This may be one reason why Mississippi, one of the poorest states in the country, has for so many years ranked among the states with the highest infant death rates.

Poverty exerts such overwhelming pressure on mothers and infants, especially Black infants, that one child health specialist warned: "It should be noted at the outset that perhaps the most important reform [to reduce] infant mortality is the eradication of poverty and discrimination in America. The refashioning and improving of existing programs for the poor are only 'interim' solutions."

While petitioners agree that the eradication of poverty would most effectively reduce current high infant mortality rates, there are known solutions which although interim could drastically reduce the current infant death rates now.

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1. 110:1027

V. HIGH INFANT MORTALITY HAS CONSISTENTLY AND SUCCESSFULLY BEEN REDUCED THROUGH ADEQUATE PRENATAL CARE; NO MAGIC WAND IS NEEDED -- JUST COMMITMENT

A. Introduction

U.S. infant mortality rates have steadily decreased since the early 1900's. Improvements in sanitation and housing, declining fertility rates, expanded access to family planning services, better nutrition and health care, and advances in medical technology have all enhanced an infant's chances for survival.

Nonetheless, the U.S. still lags far behind other industrialized nations in reducing infant mortality to the few medically unpreventable deaths. This troublesome disparity reflects the persistent prevalence of low birth weight babies, which accounts for fully two-thirds of all U.S. infant deaths.[1] A recent article published in JAMA concluded: "...unless the proportion of U.S. babies born at low birthweight is reduced, the U.S. will likely retain its relatively poor international rank."[2]

Despite this challenge, the U.S. health delivery system provides substantial incentives for technological intervention to save low birth weight babies while failing to prevent low birth weight in the first place. Not surprisingly Congress' 1980 Select Panel addresses this failure:

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[1] 139:15

[2] 47:990

> "Although improvement in survival among low birthweight infants has contributed a great deal to reduction in infant mortality, a decline in the incidence of low birthweight would result in still lower mortality and morbidity. A balanced approach to prevention of low birthweight and improvement in survival of low birthweight infants is clearly required to assure continued improvement in infant health." [1]

Indeed, dependence on technology to save low birth weight babies has gone just about as far as it can to reduce death and illness rates.[2] Only the increased availability of prenatal care to those mothers who predictably bear low birth weight babies -- low income women, minorities, teenagers -- will further reduce the U.S. infant mortality rate.

Prenatal care prevents a myriad of disabilities, illnesses and death. Universal availability of prenatal care, along with the help of medical technology when needed, is a simple, cost-effective, balanced and humane way of giving every newborn the healthiest start in life.

B. Adequate Prenatal Care Has Proven Successful in Increasing Birth Weights

> "The effectiveness of prenatal care in reducing low birthweight . . . has been

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1. 76:33
2. 76:32-33, 93:ix-xi; 112:126; 47:990

> so well demonstrated in various well-controlled studies that even the most skeptical reviewers of the health services literature would agree that this form of preventive care is one of our most valuable in promoting child health." 1

Evidence from other countries demonstrates the strong relationship between widespread availability of quality prenatal care and the birth of fewer underweight babies. In Sweden, for example, comprehensive prenatal care is uniformly of high quality and available to all. Between 1970 and 1976, when the U.S. low birth weight was 7%, Sweden's was 4.1%. This includes babies born to Sweden's growing immigrant population[2] which constitutes nearly 10% of the births.

When U.S. pediatricians at the recent U.S.-China Joint Health Committee meeting suggested a cooperative study of the low birth weight issue, the Chinese "indicated that they simply did not have enough of that problem to merit study." In China, "every effort is made through nutrition, social support, medical care and other means to assure a mature, healthy infant and mother."[3]

Many of the techniques that have worked so well in other countries have been used in the U.S. with equally positive results. For example:

-- A Maternal and Infant Care (MIC) project in New York City reduced the rate of low birth weight infants from 21.9% to 15.6% in only two years.[4]

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1. 138:165
2. 139:15
3. 12
4. 54

-- The low birth weight rate for participants in a Cleveland, Ohio MIC project was 11.7% compared to 14% for those born to a comparable group of women who were not in the program. The program also reduced school drop-out rates after delivery and decreased the subsequent pregnancy rate from 7.9 to 3.5%. [1]

-- In 1973, the St. Paul, Minnesota MIC program began a comprehensive prenatal school-based clinic for teens, 13-18 years old. Low birth weight infants were born to 5.5% of those mothers compared to 13.9% in a comparable group of teens receiving care in a non-school MIC clinic.[2]

-- In 1972, a nurse midwifery program was established in a four-county area of rural Georgia to provide prenatal care to low-income women who had no private physician. The program nearly halved the incidence of low birth weight in that region from 24% to 13.8%.[3]

-- The Obstetrical Access Project in California provided comprehensive prenatal, delivery and postpartum care to women in thirteen underserved counties from 1979-1982. Preliminary data for the project's first years show that OB Access patients had half the incidence of LBW compared

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1. 131:155
2. 6:33
3. 118:495

to a matched group of Medi-Cal patients (3.9% v. 7.3%). Striking differences were found among OB access patients in direct relation to the amount of care received. LBW rates were substantially lower for women who began prenatal care in the first trimester, as well as for those who received the full package of comprehensive services (2.8%) compared to those who only had a partial package (7.2%).[1]

-- Lincoln Hospital located in the impoverished South Bronx established a special clinic with MIC funds to provide comprehensive, family-centered prenatal care for Hispanic and Black teenagers. In the first year of the program, LBW was cut by two-thirds, from 18.1% in 1976 to 6.3% in 1977.[2]

-- Su Clinica Familiar, a migrant primary health care clinic, was established in 1972 in the Texas Rio Grande Valley. The clinic offers culturally sensitive, comprehensive perinatal health care to its predominantly Mexican-American clientele. The incidence of LBW among clinic deliveries was 4.4%. The rate of premature births was 3.5%, contrasted to 7.6% for all births in Texas, and 7.4% for the U.S. in 1976.[3]

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[1] 91:52-59
[2] 44:32
[3] 100:26

-- The Oakland Perinatal Health Project (OPHP) in Oakland, California has been providing comprehensive clinical, outreach and support services to low income pregnant women and their infants up to one year of age since 1978. A December 1982 report evaluating three years of the program found that for OPHP patients who had ten or more prenatal visits, the LBW rate was 3%; for those with 5-9 visits, 10.1%; and for less than five visits, the LBW rate was 12.4%. There was a 13.6 gram increase in birth weight for each prenatal visit.[1]

These are but a few examples of the hundreds of projects which have demonstrated prenatal care's powerful capability to reduce low birth weight.

C. Prenatal Care Also Helps Prevent Mental Retardation and Other Disabilities

Mental retardation is highly associated with prematurity and low birth weight. LBW babies bear an increased risk of cerebral palsy, deafness, mental handicap, epilepsy, autism, congenital malformation, as well as less severe handicaps known as "minimal brain dysfunction."[2] Women at highest risk of bearing mentally retarded children are younger than 16, older than 40, inadequately nourished during pregnancy, obtain poor or no prenatal care, and have few economic resources.[3]

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[1] 3:1-2
[2] 153:50
[3] 24:2-3

President Kennedy's Committee on Mental Retardation concluded that at least fifty percent of mental retardation originates prenatally or just around birth and could be prevented by improved maternal and infant care alone.[1] In addition, recently developed medical technology not commonly available when the Kennedy Committee convened further enhances the preventive capability of prenatal care. Tests can detect genetic abnormalities such as Down's Syndrome (responsible for nearly 30% of all severely retarded children in the U.S. and Western Europe),[2]sickle-cell anemia (primarily affecting Blacks), neural tube defects (spina bifida, a condition of spinal cord defects), and anencephaly (a condition where the fetus has no skull).

Further prevention of retardation and disability, then, requires enhanced availability of comprehensive prenatal care.[3]

D. What Constitutes Comprehensive Prenatal Care?

The successful programs mentioned above all provide comprehensive prenatal care. These services include clinical checks and laboratory tests, nutritional assessment and counseling, health education, childbirth preparation, psychological counseling, and education in breastfeeding and family planning. A comprehensive approach promotes optimum physical and emotional

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1. 153:8
2. 33:216
3. 153:17

well-being during pregnancy, provides personalized education and counseling, detects, treats and monitors any condition that could endanger the life or threaten the health of either the pregnant woman or fetus, monitors fetal well-being and growth, and prepares the woman for labor, delivery and care of her newborn.

Comprehensive prenatal care is usually provided by one or several health care practitioners working as a team with a physician including nurse-midwives, nurse practitioners, public health nurses, physician's assistants, nutritionists, health educators and social workers. These practitioners emphasize prevention and education. Ideally, they are culturally sensitive, bilingual when appropriate, and respectful of clients and their needs. They provide ample time to listen to an individual patient's concerns, answer questions and make timely referrals to other practitioners or specialists when necessary.*

1. Timing of prenatal care

The first prenatal visit should be made within the first three months of pregnancy. For healthy, normal women, prenatal appointments are generally scheduled on a monthly basis through the seventh month, every two weeks during the eighth month, and once a week in the ninth month of pregnancy.

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* According to the National Ambulatory Medical Care Survey, 32% of prenatal care visits in private physicians' offices involved five minutes or less, and 69% involved 10 minutes or less. There was some medical counseling in 25% of the visits and some nutrition counseling in 14%. 138

2. Clinical Prenatal Care

The first prenatal visit includes taking a complete medical history of the pregnant woman and her family, a Pap smear, a gonorrheal culture (gonorrhea can cause blindness if present in the birth canal during delivery), a pelvic exam, blood pressure and diagnostic laboratory tests. Three-quarters of the factors that lead to low birth weight can be evaluated in the first visit and appropriate intervention such as nutrition counseling, can begin early to reduce risks.[1]

Prenatal visits routinely include blood pressure checks and blood* and urine** lab tests to screen for a variety of conditions which, if left undetected and untreated, can cause major problems to the woman and fetus before, during and after birth.

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* Blood tests detect anemia (a cause of low birth weight), rubella (causes birth defects, such as heart disease, deafness and mental retardation if contracted in the first trimester), syphillis (deformities, prematurity, fetal death), and Rh factor incompatibility (causes fetal heart failure, stillbirth, severe anemia, deformity or mental retardation if an Rh negative woman, carrying an Rh positive fetus, has not been properly treated to prevent fetal damage should blood mixing occur before or during labor.)

** Urine tests determine excessive sugar (diabetes), protein (toxemia), and urinary tract infections. About 60% of all cases of urinary tract infections (kidney or bladder) can be prevented through early detection.[2] Untreated, the infection increases the likelihood of premature birth and perinatal mortality. In one Maternal and Infant Care Project, urinary tract infections occurred more than twice as often in the comparison group as in the study group.[3]

[1] 138:165
[2] 101:216
[3] 6:34

Pregnant women who have little or no prenatal care often suffer from anemia and toxemia, two conditions commonly related to LBW and ones easily detected through routine blood and urine tests. The most frequently reported risk for women in the California Obstetrical Access Project, for example, was anemia.[1] Since greater demands are made on the blood supply during pregnancy, anemia, a form of iron deficiency, is fairly common. Although all women are prone to anemia and may require additional iron during pregnancy, low income women who have closely spaced pregnancies or improper diet are at highest risk.[2] Many of these women are already anemic before pregnancy and never catch up when they become pregnant. If left untreated, severe iron deficiency anemia can result. This condition is associated with increased LBW, since the baby does not receive sufficient nourishment.

Anemia can easily be controlled with good prenatal care, iron supplementation and foods rich in protein, vitamins and iron. This was recently demonstrated by the Oakland Perinatal Health Project. Of the prenatal clients who had a low hematocrit score (a measure of the relative amounts of iron in the blood which carry oxygen to all cells in the body) at their first prenatal visit, 91.7% had a healthy rating by their final visit.[3]

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[1] 91:64
[2] 101:216
[3] 3:30

Toxemia occurs only in human pregnancies. Rarely seen before the 24th to 30th week, toxemia is characterized by high blood pressure (hypertension), protein in the urine, and swelling. About 7% of pregnant women in the U.S. develop toxemia.[1] If not treated, it can progress to its most severe form, eclampsia, causing maternal convulsions and coma, which can result in permanent disability or death for mother and infant. Toxemia is most prevalent among low income women who do not have access to adequate prenatal care.[2] Diabetic, hypertensive, adolescent women, those carrying more than one baby, or who suffer from poor nutrition and stress, are especially prone to developing toxemia. This condition contributes to LBW infants, whose growth is retarded because the placenta is unable to provide sufficient circulation to the fetus. High quality prenatal care, good nutrition and adequate rest are the best ways to prevent toxemia. An MIC Project for teenagers in Minnesota found the toxemia rate for adolescents in the study group to be 11.1% while the rate for those in the comparison group was 16.7%.[3]

Diabetic mothers tend to have either very large or very small babies which are at increased risk of perinatal death, usually from serious respiratory problems, one of the most life-threatening complications in LBW infants. These risks, too, can be greatly reduced with early, continuous, comprehensive care, insulin and diet.

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[1] 18:75

[2] 18:81

[3] 6:34

E. Additional Components of Comprehensive Prenatal Care Contribute Significantly to Improving Pregnancy Outcome

1. Nutrition

The health of an infant at birth reflects the nutritional status of the mother before and during pregnancy. Recently, the role of adequate maternal nutrition has undergone considerable scrutiny. Many health experts now concur that the quality and quantity of food consumed during pregnancy is critically important, particularly for low income women who have few resources and possibly a lifetime of poor nutrition.[1]

Infant birth weight is significantly affected by the mother's weight before pregnancy, weight gained during pregnancy, and the age of the baby at birth.[2] Fully one-third of LBW in the U.S. is believed to result from retarded fetal growth during pregnancy.[3] Poor nutrition accounts for at least 57% of LBW in Black newborns.[4] Nutritional deficiencies in pregnancy are also related to increased vulnerability to illness, anemia and mental retardation.

Over the last 35 years, various food supplement programs have demonstrated that improved nutrition makes a big difference. In 1948, the Montreal Diet Dispensary began providing milk, eggs and oranges to low income women registering for prenatal care in public clinics. Of 1736 participants from 1963 to 1972, 80% of the women suffered from poor nutritional status when enrolled, and 25% were underweight by 5% or more when they became pregnant. Significant increases in birth weight for all women considered to be at special risk (teens, underweight and overweight women) were achieved. Furthermore, the earlier the intervention began, the better its affect on birth weight. The rate of LBW for mothers in the program for 1-12 weeks was 9.8%, compared to 4.07% for women who received supplementation over 20 weeks. Teens in the program had a LBW rate of 3.3% contrasted to 10% in a comparable group that did not receive food supplements. Perinatal mortality dropped from 26.6 to 8.3/1000 live births. The rate of developmentally disabled infants born was lower than the average for all of Canada. This program was one of the first to demonstrate how the poverty cycle can be broken and the effects of previous poor pregnancies mitigated.[1]

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[1] 67:1
[2] 72:7,8
[3] 127:31
[4] 65:347

In the U.S., the Women, Infants and Children (WIC) food supplement program was authorized by Congress in 1972. Modeled after the Montreal Diet Dispensary program, WIC provides food and nutrition education to low income, pregnant and nursing women, infants and children up to age five.[1] WIC attempts to reach those individuals who, because of inadequate nutrition, face an increased risk of complications during pregnancy or poor fetal growth and development. WIC's goal is to decrease the rate of LBW infants who require hospitalization in costly neonatal intensive care units. By 1977, WIC was serving over one million women, infants and children at an annual cost of about $423 per participant.

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[1] 67:1

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Evaluations of the WIC program establish incontrovertibly its cost-effective, successful role in preventive health care.

> "In Michigan, 30 percent of the high risk women were anemic before they came into the WIC program. After participation, the figure was six percent . . . . In the Pennsylvania WIC program, the infant death rate was 10.6% before participation . . . it was zero after participation. Premature birth rates decreased from 12.8 to 1.6 percent. And pregnancies with complications were reduced from 30 to 17.6 percent".[2]

Six WIC sites and three non-WIC sites in Massachusetts were studied between 1973-78 by the Harvard University School of Public Health. Information was collected on a total of 1328 pregnant women, 918 WIC and 410 non-WIC participants. The LBW rate for WIC babies was 3.4%, compared to 14.6% for non-WIC infants.[3] Further, birth weight improved with each additional

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1. 71
2. 52:8
3. 71:9

month of food vouchers. The authors reported, "If the full complement of nine WIC vouchers were received by prenatal participants, birthweight would increase by eleven ounces."[1] The authors showed that for every dollar invested in the WIC program, at least three were saved in later treatment costs.[2]

Programs providing comprehensive prenatal care to low income women routinely include nutrition evaluation, counseling and when necessary referral to WIC or other food supplement programs (e.g., food stamps). The nutrition component of the California Obstetrical Access pilot project was so successful (85% of the women in the program participated) that a recent cost-effectiveness evaluation of the program recommended expanding the Medi-Cal (Medicaid) obstetrical benefit package to include nutrition, as well as other support services.[3]

National health goals established by the federal government for 1990 include marked improvement in the nutritional status of pregnant women based on the assumption that "current efforts to ensure an adequate supply of food will be continued and extended (WIC and food stamps)."[4]

2. Health Education

Smoking, alcohol and use of drugs during pregnancy also affect low birth weight, birth defects, retardation and disability. While many women are quite receptive to practicing good health habits during pregnancy, many are unaware of the adverse consequences of smoking, alcohol, and drugs. Comprehensive prenatal health education should cover: smoking, alcohol and drugs, as well as nutrition counseling, the physiological aspects of pregnancy, safe remedies for the discomforts of pregnancy, counseling for stress, environmental hazards at home and in the workplace, breastfeeding education, family planning including the importance of spacing births, and childbirth preparation. Ideally, educational sessions are scheduled to coincide with regular prenatal appointments.

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[1] 72:35
[2] 71:45
[3] 81:1-3
[4] 139:18

a. Smoking

The U.S. Surgeon General reported in 1979 that the detrimental effects of smoking cigarettes during pregnancy include increased risk of spontaneous abortion, perinatal death, prematurity, low birth weight, shortened body length, smaller head size, and potential long term impairments in physical growth, mental development and deficiencies in behavioral development in children at least up to eleven years of age.[1] Sudden Infant Death Syndrome (SIDS) is also associated with maternal smoking.[2]

Abundant evidence causally links maternal smoking to low birth weight. Infants born to mothers who smoked during pregnancy weigh about 200 grams less than those born to women who did not smoke. Fully 21-39% of the incidence of LBW is attributable to maternal smoking.[1]

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[1] 137:8
[2] 59:2

The more a woman smokes during pregnancy, the lower the birth weight of the newborn. Conversely, if a woman stops smoking at any time during pregnancy, the risk of delivering a low birth weight baby becomes similar to that of a nonsmoker.

Measured differently, an estimated 14% of all premature births in the U.S. are attributable to maternal smoking.[2] These preterm births result from other complications of pregnancy, labor and delivery which increase directly and significantly as the level of maternal smoking increases.[3]

The possibility of perinatal death is increased by 20% among smokers of less than a pack a day, and 35% among those who smoke more than a pack a day.[4] Perinatal death associated with maternal smoking involves fetal deaths due to oxygen deprivation, and neonatal deaths due to prematurity and related respiratory complications.

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[1] 137:11,27
[2] 137:42
[3] 96:495
[4] 96:495

The risks associated with maternal smoking are compounded by the effects of poverty, prior perinatal death,[1] poor nutritional status, anemia,[2] and lack of prenatal care.

b. Alcohol

Alcohol is the most commonly used drug in the U.S. Not surprisingly, alcohol-related problems are among the nation's most serious health problems.[3] In light of growing evidence that intrauterine exposure to alcohol is a leading cause of birth defects and associated mental retardation,[4] the American Medical Association officially recommended that pregnant women abstain from alcohol.[5]

Fetal damage due to alcohol occurs differently at different stages of pregnancy:

> "During the first trimester, alcohol may alter cell membranes and the embryonic organization of the tissue. Throughout gestation, direct effects of alcohol on the metabolism of carbohydrates, lipids, and protein probably retard cell growth and division. Alcohol also interferes with the active transport of amino acids across the placenta, reducing the availability of essential nutrients to the fetus . . . The third trimester is the time of most rapid brain growth. . . . High blood alcohol level concentrations during this period may impair central nervous system growth and future intellectual and behavioral development".[6]

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1. 137:28
2. 96:501
3. 106:630
4. 132:251
5. 119:33
6. 121:4

Fetal alcohol effects range from minor alterations in growth at one end to "fetal alcohol syndrome" at the other.[1] These effects include low birth weight,[2] prematurity,[3] spontaneous abortion,[4] fetal distress and neonatal depression,[5] developmental abnormalities,[6] mental retardation, and behavioral and learning problems.[7] As with cigarette smoking, decreasing alcohol consumption at any time, even in the third trimester, will significantly improve chances of having a healthier baby.[8]

Once problems drinkers are brought into the health care system, health educators skilled in eliciting information can play a role in changing behavior.* During 1974-79, more than 1700 women were interviewed at Boston City Hospital when they first registered for prenatal care. Women who reported heavy use of alcohol were scheduled for counseling sessions which coincided with routine prenatal visits. Fifty-six

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1. 86:1154
2. 86:1155; 109:138-139
3. 109:529
4. 62:174; 78:179
5. 130:143
6. 140:62
7. 126:980
8. 121:6; 132:256

* One study found that physicians are generally reluctant to ask prenatal patients about alcohol because they lack the time or knowledge about how to handle problem drinkers who are perceived as "difficult cases." 121

percent of the 39 women who attended three or more sessions achieved abstinence or significantly moderated their drinking before the third trimester. Their newborns were compared with infants of mothers who continued drinking heavily throughout pregnancy. Improvement in growth, measured by birth weight, height and head size was consistently associated with reduction of alcohol use.[1]

c. Drugs

Americans spend $5 billion every year on the more than 350,000 varieties of over-the-counter drugs.[2] The majority of these have not been tested for safety and effectiveness by the U.S. Food and Drug Administration, and drug manufacturers have not adequately determined the potential damaging effects of these drugs on maternal and fetal health. Yet, thousands of these products are used regularly to relieve the discomforts of pregnancy.

Self-diagnosis and treatment with over-the-counter drugs is an unquestioned part of U.S. lifestyle. Unfortunately, many pregnant women are unaware that no drug, either prescription or non-prescription, has been proven safe for a developing fetus.[3] The most commonly used non-prescription drugs implicated in birth defects and other complications are aspirin (damage of kidney, liver, central nervous system, bleeding), acetaminophen, or non-aspirin (kidney and liver damage, anemia, fetal death from toxicity), antihistamines (cleft palate, limb deformities), barbiturates (newborn addiction and withdrawal, liver and brain damage, respiratory distress), and cold and cough medicines (liver and bone marrow damage, blood clotting deficiencies).[1]

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[1] 121:2
[2] 30:1
[3] 84:19, 42:843

The effects of drugs taken during pregnancy depend in large part on when they are taken, the number and kind of drugs taken in combination, and the timespan during which they were taken. Fetal growth follows a specific developmental sequence. Since every part of the body has a critical formation period, anything that interferes with that process will result in arrested or deformed development. This was tragically seen during the early 1960's when women who took the poorly-tested drug Thalidomide to prevent nausea in the first trimester gave birth to nearly 6,000 limb-deformed infants worldwide.

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There are few studies which have isolated the effects of prenatal education on drugs, alcohol or smoking from the other components of health education usually included in comprehensive prenatal care. What is known, however, is that comprehensive prenatal care has significantly reduced low birth weight, much of which is caused by use of drugs, alcohol and tobacco during pregnancy. Moreover, as many health practitioners can attest, once informed of hazards, pregnant women are frequently highly motivated to protect their fetuses, even if such protection means changing lifelong habits which stubbornly persisted when only the mother's health, not her child's, was at stake. In addition to educating pregnant women, efforts to reduce drug, alcohol and tobacco use during pregnancy can be enhanced through heightened public awareness and increased popular support for the pregnant woman who changes her health habits at this critical time.

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[1] 123:31-34

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F. Underserved Pregnant Women Must be Brought Into the Health Care System

1. Women Who Are Most At Risk

While for most women, pregnancy and childbirth are a normal, healthy process, a time of personal joy and sharing with families and friends, problems do sometimes arise. Though potentially serious for mother and child, they can usually be controlled if identified, treated and monitored early enough with prenatal care. At no other time, then, is appropriate health care more important than in the nine months before birth.

Unfortunately, the advantages of prenatal care are not shared equally by all pregnant women in the U.S. In fact, the women who would benefit most from early quality prenatal care often have the most difficult time obtaining it. Teenagers, low income, minority and undocumented women are those most likely not to get needed health care, putting them at greatest risk of bearing low birth weight babies vulnerable to illness, disability and death.

The federal government has set 1990 as the year in which 90% of all women in any county or racial or ethnic group should begin prenatal care in the first trimester of pregnancy.[1] Tremendous progress must be made in the next seven years to reach that goal. In 1978, 25% of pregnant women had no prenatal care in the first trimester.[2] Only 55% of American Indian women began prenatal care in the first three months of pregnancy in 1978.[1] In 1977, only 59% of California's Hispanic women who bore children were able to obtain prenatal care in the first trimester.[2] And in 1979, while 79% of white women began prenatal care in the first trimester, only 62% of Black women were able to obtain early care.[3]

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[1] 139:18
[2] 139:15

In 1978, over half of all pregnant teenagers in the U.S. did not get prenatal care until the second trimester.[4] Teens are more likely to conceal or deny being pregnant, be fearful of admitting to sexual activity, have stressful relationships with their families, become isolated, leave school, not understand the importance of early prenatal health care and not know where to find services that are available.[5] Although pregnant teens are generally characterized as high risk and do have high complications rates, many of the risks associated with adolescent pregnancies can and have been greatly reduced with early prenatal care.[6] It is more the "social rather than the biological side of health care that places the pregnant teenager at risk."[7]

The specific problems that constitute an "at risk" pregnancy for women with inadequate or no prenatal care include medical as well as socioeconomic and psychological factors. Untreated anemia or infections, short intervals between pregnancies, inadequate weight gain, poor nutrition, smoking, misuse of alcohol and drugs, severe emotional problems, inadequate income, chronic domestic violence, and lack of an emotional support system are but a few examples of the factors that contribute to poor pregnancy results. Being at risk, however, is by no means a static condition. Accessible, quality prenatal care helps women who are initially at risk for medical, social, economic or psychological reasons to become low risk or even normal.

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[1] 139:18
[2] 95:5
[3] 104:6
[4] 60:59
[5] 21:52
[6] 21:54
[7] 79:18

2. Barriers to obtaining adequate prenatal care

Among the major reasons low income and minority women do not or are unable to obtain early prenatal care are an unawareness of preventive health care's importance, financial, uneven distribution of primary health care providers, language and cultural barriers, undocumented status and transportation difficulties.

a. Understanding the importance of prenatal care

> "Sometimes health care programs must do more than provide an open door. They must take the initiative to find, educate and help bring in mothers and children to receive care."[1]

It is often difficult to convey the value of preventive health care in communities where people lead crisis-ridden lives due to poverty, poor housing, unemployment, and daily struggles to obtain food.[1] In this context, health care only becomes a priority in an emergency, and the significant relationship of prenatal care to the outcome of pregnancy is not necessarily known.

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[1] 138:180

In some cultures, pregnancy is viewed as a natural condition requiring no medical attention. A 1970 survey of 1500 low income, predominantly Mexican-American women in San Antonio, revealed that only one-third of those questioned appreciated the importance of prenatal care.[2]

The Coalition to Fight Infant Mortality, petitioners in this action, advocate more community education.

> "A lack of community awareness about the need for early and consistent prenatal care prevents many women from seeking such care. A lack of education programs about their prenatal health needs also prevents many women from properly maintaining their health during pregnancy. It is not solely the responsibility of these women 'to become educated' about their perinatal needs. Health education is the responsibility of the health care system and must be a major component of . . . perinatal services."[3]

Thus to be effective, programs offering quality prenatal care to low income women must be able to bring women into the health care system. This requires active and ongoing community education and outreach.

The Denver, Colorado MIC program involved community

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1. 73:997
2. 53:38
3. 31:84-85

outreach workers in recruiting clients into prenatal care. The outreach workers educated the clinic's professionals about the community's lifestyle and values and conveyed to the community the importance of the health program. After only four months in one neighborhood, over 60% of the MIC clinic participants had been referred by the outreach workers and use of clinic services was 12% higher in neighborhoods with outreach workers. Fifty percent of the patients were seen in the first or second trimester in neighborhoods with outreach workers, compared to 32% in unserved neighborhoods.[1]

When prenatal programs are acceptable to a community, the response can be overwhelming. Mission Neighborhood Health Center in San Francisco found that its bilingual/bicultural prenatal health education classes "proved to be one of the major attractions of our project ... the major means of advertising was word of mouth through the patients themselves .... We didn't even need to do as much advertising as we did initially to get people involved."[2]

Yet, even when women do understand how important prenatal care is, numerous other barriers can prevent them from obtaining services.

b. Financial barriers to prenatal care

> "Despite the positive effects of Medicaid and various formula and project grant programs, financial barriers remain responsible for many of the most serious

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[1] 73:1001
[2] 144:78-79

> and persistent inequities in maternal and child health care."[1]

The high cost of health care is cited repeatedly as the predominant barrier preventing low income pregnant women of all ages and ethnic backgrounds from receiving needed prenatal care.[2] Medicaid provides coverage for fewer than 75% of the poor in the U.S.[3] It has been estimated that 220,000 need Medicaid coverage for pregnancy and delivery but are not eligible. Of these women, approximately 60,000 are pregnant for the first time.* When the infants are born, the mothers will then qualify for AFDC and Medicaid but during the crucial early months of pregnancy in many states these women are not Medicaid eligible. The remaining 160,000 women are financially needy but for a variety of reasons, including living with a poorly paid but employed spouse, do not qualify for Medicaid.

But even having Medicaid is no guarantee that pregnancy health care can be found. Physician participation in the Medicaid program is strictly voluntary. Each year, fewer and fewer physicians are willing to accept Medicaid patients.[4] This occurs despite an oversupply of doctors in the U.S.,[5]

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1. 138:37
2. 95:2; 31:18; 23:48; 53:39; 21:35-40
3. 138:31
4. 29
5. 138:13

* H.R. Rep. No. 568, 96th Cong., 1st Sess. 85 (1979).

particularly specialists such as OB/GYNs. In California, for example, the number of OB/GYN's accepting Medi-Cal patients dropped from 65% in 1974 to 46% in 1977.[1] And, the unavailability of doctors for Medicaid patients is exacerbated by the tendency of physicians to concentrate their practices in populated, affluent metropolitan areas of the country, leaving a severe health care shortage in the inner cities and rural areas.

Physicians' reluctance to accept Medicaid is mainly rooted in the disproportionately low reimbursement rate (approximately 1/3 of the private fee paid)[2] for normal prenatal care and delivery. Yet in 1981, a total of $255 billion was spent for health care in the U.S.; 42.7% of that total was paid with public dollars.[3] Despite the huge amount expended, only a fraction was allocated for the preventive care needed by pregnant women.

> "Foremost is the fact that preventive services are generally not covered by either private or public insurance ... Present incentives drive many providers to offer the most expensive and least prevention-oriented types of care, which are particularly inappropriate for children and pregnant women."[4]

The situation is even more desperate for women who are not eligible for Medicaid. These women are forced to rely on local public health care provided by counties and limited-term Maternal and Child Health programs funded by the federal government and the states. In the absence of these services, women may have no other option than to forego prenatal care altogether, wait until the last month to get some care, or show up at a hospital emergency room in labor.

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[1] 23:123
[2] 21:253
[3] 63:1
[4] 138:31

Many physicians, hospitals and even local public health departments will not accept non-insured women without advance, out-of-pocket payment.[1] One year after Los Angeles County began charging uninsured county patients $20-30 for each prenatal visit, one county hospital reported that 65% of women delivering there had no prenatal care. The broken prenatal appointment rate in the county increased by 73%, and 147% during the ninth month of pregnancy. Most telling, the number of premature births at the county's three hospitals rose by 7.4%.[2]

c. Limited access to primary care and nurse-midwives

Limited and unequal access to primary medical care in the U.S. has been a growing concern for the last two decades. The federal government and Congress have attempted to correct this imbalance through the development and financial support of formal education programs to train a variety of mid-level practitioners (nurse-midwives, nurse practitioners, physicians assistants) for work in expanded maternal health primary care roles.*

These efforts have suffered cutbacks. Even when more

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1. 21:36
2. 36:25

* Nurse Training Act, 1964, National Health Service Corps. Act, 1970, Comprehensive Health Manpower Training Act, 1971.

federal dollars were available, only a small number of nurse-midwife students were accepted by programs for training each year-- not enough to meet the desperate need for practitioners in maternity care, particularly for low-income women. In California, for example, the three nurse-midwifery training programs accept a total of only 25 applicants annually.[1]

Unfortunately, no matter how many more are trained, the benefits of nurse-midwives will not be realized until barriers which prevent their full utilization are removed. The GAO and the House Subcommittee on Oversight and Investigations of the Committee on Interstate and Foreign Commerce both found numerous factors which prevent nurse-midwives from using their full range of skills. Those barriers identified are: physician resistance, limited availability of physician backup, restrictive state licensing, third-party reimbursement, and the inability of nurse-midwives to obtain hospital staff privileges.

In a 1979 report, the GAO recommended that "...HEW encourage a greater use of nurse-midwife/obstetrician teams, help eliminate barriers which preclude nurse-midwives from practicing in hospitals, and provide additional training funds for nurse-midwives, by giving such training higher priority for use of existing funds and/or seeking additional funds from Congress."[2]

d. Language and cultural barriers to health care

The scarcity of health providers who serve non-English speaking clients in their own language presents a serious obstacle to many pregnant women. Inability to communicate with a health care practitioner puts women at unnecesary risk and effectively renders health care inaccessible.

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[1] 21:175
[2] 134:263

> "First, the limited English speaking person is ignorant of various benefits and services since information is primarily disseminated in English. Second, if the limited English speaking person has some knowledge of . . .her entitlements, since eligibility determinations are part of [establishing] their needs with English-only forms . . . she may be found ineligible incorrectly. Then, assuming that the limited English speaking person makes it through these two hurdles, diagnosis and treatment is also impossible due to monolingual English professional staffs. Family members and volunteers serving as interpreters are not adequate."[1]

In some instances, it is culturally unacceptable for women to receive care from a male physician. Often Hispanic, Southeast Asian and Middle-Eastern immigrants, accustomed to receiving health care from women practitioners, are reluctant to seek prenatal care from male providers. In a survey conducted in San Antonio, Texas, 35% of the Hispanic women respondents expressed "strong concern or fear regarding physical examinations",[2] In another study, it was felt that, in part, Hispanic women received late or no prenatal care due to "insufficiency in numbers of Hispanic health care providers who might establish cultural rapport".[3]

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1. 108
2. 53:39
3. 95:2

Racial and class discrimination further discourage many women from seeking and obtaining prenatal care. In a survey conducted by the Coalition to Fight Infant Mortality, the third greatest barrier identified was "attitudes and insensitivity of caregivers, and in particular the negative attitudes towards women and ethnic minorities".[1]

e. Undocumented women

There are an estimated 7.4 million undocumented people in the U.S. of which about 60% are from Mexico.[2] For undocumented women, the usual problems associated with getting prenatal care, i.e., money, availability of services, awareness of the value of care, language, and discrimination, are compounded by fear of deportation which prevents all but a few undocumented people from using public health or social assistance services. California estimates that only 1% are on welfare and only 4% use public schools or apply for unemployment benefits.[3] In 1979, an estimated 90% of undocumented people in the U.S. were employed.[4] In California alone, undocumented workers contributed $1.5 billion in state taxes in 1979.[5] Yet, even women who are legal residents and eligible for Medi-Cal are reluctant to apply for fear of endangering other family members who are undocumented.[6]

Most of the 1.5 million undocumented persons who reside

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1. 31:16
2. 23:156
3. 23:156
4. 23:157
5. 23:159
6. 21:50

and work in California[1] turn to county health services. The closure of 30 county hospitals since 1966 has foreclosed access to health care for many undocumented persons, particularly in the rural and agricultural areas of the state.[2]

Undocumented women's need for increased access to maternity care was starkly documented in California's Obstetrical Access Project. While the planners had anticipated that the vast majority of the participants would be Medi-Cal, in fact 53% of the program's 1,980 registrants during its first year of operation were low income, non-Medi-Cal eligible. Hispanics comprised nearly half of all OB Access enrollees.[3]

f. Transportation

> "Sometimes health care providers and facilities are only theoretically available. Long distances or high costs in getting to a source of care can be major barriers to obtaining needed health services. For the poor, the distance appears to be a significant deterrant to seeking preventive care."[4]

Reliance on public transportation entails high cost and long travel time to facilities located inconveniently in relation to public transit routes.[5] For mothers who cannot arrange childcare, traveling with small children intensifies the stress of a long trip.

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1. 23:156
2. 21:2
3. 91:3,27
4. 138:181
5. 21:32

Fifteen hundred women surveyed in San Antonio indicated that transportation problems were among the factors which frequently interfered with their use of prenatal care services.[1] Another study reported that low income people spent 58% more time traveling to medical facilities and waiting to see a doctor than people with adequate financial resources.[2]

Transportation is even more problematic in rural areas. Poor women in central California, dependent upon public buses transfer several times to get to their prenatal appointments; many are unable to return home the same day.[3] In many rural communities, there is simply no public transportation at all. One MIC project in Augusta, Georgia significantly alleviated that problem by allocating project funds to provide transportation for patients who lived within 100 miles of Augusta to get to and from prenatal care visits and delivery.[4]

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1. 53:38
2. 35:81
3. 21:34
4. 14:428

G. There are Excellent Models for Providing Effective, Comprehensive Prenatal Care to Low-Income, Minority Women

The success stories of programs across the country which have effectively provided comprehensive prenatal care to low-income women are legion. Petitioners have selected some to be told; together, they address the diversity of cultural, socio-economic and geographic factors which must be taken into account when designing a prenatal service which can reach poor, pregnant women and significantly reduce the incidence of low birth weight.

Obstetrical Access Pilot Project

The Obstetrical Access (OB Access) Pilot Project in California was a legislative response to the diminishing numbers of physicians willing to accept Medi-Cal patients and to the documented inability of many low income women to obtain prenatal care, whether or not they were eligible for Medi-Cal.[1] Launched in 1979, OB Access combined funding from Medicaid and Title V to award existing community and county clinics' funds for comprehensive community-based services. In its first three years, OB Access has provided prenatal, delivery and postpartum services to nearly 7,000 women in thirteen underserved counties in both rural and urban areas of California.

In San Diego, for example, a consortium of eleven community clinics, the U.S.C. San Diego Hospital, and the San Diego Department of Public Health Services became the OB Access program which

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1. 91

by 1981, was seeing nearly 1500 women each year.[1]

Ten midwives provide routine prenatal care at the various clinic sites. Infant care pediatric clinics are conducted every week. Administrator Ann Bush described the program:

> "At the midwife-run clinics we provide nutritional assessment and counseling of all our patients, psychological counseling ... and extensive health education .... About 60% of the total patient load is Spanish-speaking, another 10% is Indochinese . . . . Almost all of the staff dealing directly with the patients are bilingual. ... When the patient comes in to deliver at University Hospital, she has the option of having her baby in an alternative birth center setting or the labor rooms .... About 80% of our patients are delivered by the midwives."[2]

The prenatal coordinator of one participating clinic described the services provided:

> "Nutrition is really stressed and reinforced ... with the WIC program. Breastfeeding is stressed and reinforced by the home visits of our pediatric nurse. Prenatal care is ... individualized. The health educators see people on an individual basis. We have the LaMaze classes available. They are part of the package."[3]

The OB Access Project also covers a 10,000 square miles, three-county area in rural Northern California. A sizeable number of patients are migrant or undocumented workers. Dr. Thomas Dodson, director of both the area's OB Access and WIC programs, notes that the project provides whatever is necessary for low-risk, no-risk, or high-risk mothers and infants.

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1. 91:128-129
2. 19:128-129
3. 70:130-131

> "We are finding that the earlier we get them . . . into the program, we are having much healthier babies . . . much healthier mothers. Currently . . . any OB Access mother . . . is automatically put on the WIC program . . . We cover all the aspects of perinatal development . . . the whole concept of birthing from conception through to birth. . . . We urge and encourage the fathers to be there. . . . I think it's indicative that we have a waiting list . . . As word of the program gets out . . . we are finding that our program is being somewhat overwhelmed by the response." [1]

Statewide results of the first year of OB Access were overwhelmingly favorable.[2] Low birth weight rates were half those of comparable Medi-Cal patients, and 86.2% of the women began prenatal care in the first two trimesters. In previously underserved areas, a high percentage of low income women received a full package of services. Such positive results provide strong evidence that comprehensive, integrated care is far more effective in reducing low birth weight than the typical Medicaid approach.

Su Clinica Familiar[3]

An excellent model for serving the Hispanic maternity population is a nurse midwifery service established in 1972, Su Clinica Familiar in the Texas Rio Grande Valley. Within its

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1. 41:34-35
2. 91:2
3 100:25-29

first three years, Su Clinica midwives were delivering nearly 80% of the births in the entire county. Su Clinica's quality prenatal care has lowered toxemia to only a few cases (2.9%) and reduced low birth weight, which is substantially less frequent than the rate for Texas and the country as a whole.

Family-centered comprehensive care is provided from pregnancy through delivery and into the first few weeks after birth. All family members are encouraged to stay with the woman while she is in labor, along with a nurse or nurse midwife who is in constant attendance.

> "The support of loved ones during the work of labor and in the face of intense physical readjustment cannot be measured. . . . Every effort is made to eradicate fear which plagues many laboring women who are left alone . . . . Our nurse midwives . . . listen to the repeated testimonies of mothers saying that the best alleviation of pain in labor comes from being attended by persons who show personal interest and give them constant support."

Upon discharge, a nurse or nurse-midwife makes two follow-up home visits to ensure all is well and to answer any questions. Of 753 live births at Su Clinica between 1972 and 1976, 98.7% of the mothers and infants were visited in their homes following delivery. Migrant workers who left the area shortly after the birth were referred to other migrant health clinics for continuity of postpartum and neonatal care.

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Lincoln Medical Center Teen Pregnancy Clinic[1]

In the South Bronx, Lincoln Medical Center's nurse midwifery service established a special evening clinic for teenagers in 1975. The Center addressed the special needs of pregnant teens, including providing clinic access during non-school hours. The opening of the special evening clinics was announced to this low income community (70% Hispanic, 28% Black) through handouts at local high schools and via the local newspapers, radio and television stations.

Each prenatal session commenced with a half-hour class for the patients, their family and friends on subjects including nutrition, labor and birth, the physical care and mental stimulation of the newborn, and family planning. Health education materials in Spanish and English included such practical topics as "Good Foods for Pregnancy and Breastfeeding", "Lovemaking in Pregnancy" and "Heartburn".

The program became so popular that registration had to be limited to adolescents 17 years or younger. Among the 204 teens cared for in the first two years of the program, the low incidence of toxemia (4.7%), LBW rate (6.3%), and high number of prenatal visits (93% had six or more) attest to the success of this approach with teenagers.

Booth Maternity Center Clinic for Pregnant Teens[2]

Convinced that individualized, comprehensive care would

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1. 44:27-32
2. 37:68-71

reduce the maternal and infant complications often found in pregnant teens, the Booth Maternity Center in Philadelphia instituted a special program in 1979 for teens, who comprise 8% of the Center's 1200 births each year.

A nurse midwife follows each patient through pregnancy and delivery. Group sessions cover such topics as nutrition, fetal development, labor and delivery, parenting, and family planning. If, however, a teen has a problem or question, addressing the immediate concern automatically takes precedence over the scheduled discussion. Role playing and films are used to engage interest in abstract issues, such as how a support person can help to ease labor. At the sessions,

> " . . . pregnant teens are encouraged to bring along a special friend or relative who will become a labor coach or support person during labor and delivery. At first, the pregnant teen may react to the idea of a support person with resistance and embarrassment ('I don't want anybody to see me go through all that'). Nonetheless, by the time of delivery, every teen in our program has a support person."

A support person present often means a shorter labor and a decreased need for drugs and other interventions. Involving a family member helps alleviate family stress due to the pregnancy and fosters interaction with other parents of pregnant teens. And, every effort is made to involve the father of the baby in the labor and delivery to enhance bonding between him and the

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newborn.

This group of teens was compared to other teens at Booth who were not in the special program. Both groups had nearly the same distribution of prenatal problems, but the special program participants made significantly more prenatal visits, had fewer complications in labor and delivery, shorter labors and none required general anesthesia or forceps. They also had lower rates of maternal and neonatal morbidity, higher rates of postpartum checkups, greater acceptance of birth control and higher rates of breastfeeding. The number of premature births was not significantly different (4% v. 6%), but both fell way below the national average of 14% premature births born to teenage mothers, thus attesting to the excellent care Booth provides for all of its teenagers.

Oakland Perinatal Health Project[1]

In 1978, Governor Jerry Brown responded to alarming rates of low birth weight and infant mortality in the low-income Black and Hispanic communities of Alameda County by directing the California State Department of Health Services to initiate the Oakland Perinatal Health Project (OPHP). The Project funds a full range of prenatal, support and pediatric services through ten county and community clinics. Nutrition services at the clinics are tightly coordinated with the county WIC program. OPHP also has developed educational materials, conducts training, and has launched a local media program.

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[1] 3

By 1982, over 1,700 women had enrolled in one of the OPHP clinics for prenatal care, including 24.9% Black, 24.8% Hispanic, 5.4% Native American, 15.6% Southeast Asian, and 21.2% white patients.

OPHP's midwifery program and alternative birthing rooms at the county hospital caught on quickly. This service has been credited with increasing the number of deliveries at the county hospital from 560 in 1978[1] to nearly 1,000 in 1983.[2]

> "I received my prenatal care at the midwifery health clinic and was referred to them because of two miscarriages I had earlier.. I chose to go through the midwives because of different people's experiences with them. I had a very close relationship. Each time I went in, they told me what was happening ... where the baby's head was, how much I weighed, what I should do and what I shouldn't do. And one of them was with me during my labor and the moment I went into the hospital until the delivery and afterwards ... I had three older children with me in there during the delivery along with my sister and a friend and my husband, and the experience was incredible." [3]

Sixty-one percent of the OPHP clients were Medi-Cal or had eligibility confirmation pending, 17.4% were uninsured, and 9% had private insurance. Some of the privately insured women selected OPHP for the nurse midwives and comprehensive care not generally found in the private sector. One woman explained:

> "The main reason I went to a midwife [was] I tried two private doctors and they didn't give me the time. This is my first child and I didn't know anything about having a baby. So they were very helpful. They showed me different books on how to

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1. 2:60
2. 116:128-129
3. 4:29-30

> deliver. I wanted to breastfeed my baby. They showed me how to do that ... [When] I had problems trying to breastfeed .... they were there .... They came over to the house .... to show me. A private doctor wouldn't do that."[1]

And another said:

> "I have private insurance, but I chose to go to the East Oakland Family Health Center because [of] ... the midwifery services ... private physicians ... [and] the different programs they had to offer. I can't stress enough the importance of a woman having these choices. ... And that's why I received my care there instead of going to a private doctor's office."[2]

OPHP successfully reduced LBW among its socioeconomically high-risk population. Now in its fifth year, OPHP is the first demonstration project in California to receive funding beyond the usual three-year cycle.

Nurse Midwife Programs

Comprehensive prenatal care and nurse-midwives frequently go hand-in-hand. Many industrialized nations with infant mortality rates far below the U.S.'s rate rely primarily on midwives to handle normal pregnancies and deliveries and only refer complex cases to specialist obstetricians whose training emphasizes management of high risk women. In Norway, nearly 96% of pregnant women receive care and delivery from midwives; in England, 70%.[3]

In the United States, nurse midwives have faced serious opposition since the turn of the century resulting from pro-

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1. 132A:31-32
2. 52b:30-31
3. 56:11

fessional power struggles and major social, cultural and economic changes in the provision of maternity care,[1] especially the rise of hospital-based obstetrics. Nonetheless, during the last twenty years, many consumers have questioned modern birth practices as unduly interventionist, impersonal and expensive, and have increased their demands for midwives. Yet, even though women of all income levels and ethnic backgrounds, have enthusiastically accepted nurse-midwives,[2] they still face considerable obstacles to practice from physicians and hospitals, particularly in the private sector.

Where permitted to practice, professionally trained midwives have maintained a longstanding tradition in this country of providing low cost, quality care to low income pregnant women.

Frontier Nursing Service [3]

In 1925, English-trained Mary Breckenridge opened the Frontier Nursing Service (FNS) in eastern Kentucky to bring primary health care to impoverished Appalachian women. In its first seven years, the FNS provided prenatal care and delivery to 1000 women and so dramatically reduced maternal and infant deaths in the area that the Metropolitan Life Insurance Company declared in 1932 that "if such services were available to the women of the country generally, there would be a saving of 10,000 mothers' lives a year in the U.S., there would be 30,000 less stillbirths and 30,000 more children alive at the end of the first month of life."[1]

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[1] 21:161
[2] 151:4-5; 129:2; 40:85
[3] 15:14-17

In 1970, the service was expanded to include entire families. Today, FNS is a network of rural nursing outposts, each linked to a nearby primary health care center. Each outpost is primarily staffed by a nurse-midwife who provides prenatal and postpartum care and, when necessary, home delivery.[2]

Maternity Center Association

The Maternity Center Association began providing maternity care to poverty stricken immigrants living in New York City tenements in 1914, and opened a nurse midwifery service and training program which continues today. Between 1931 and 1951, 5,765 women received care at MCA. Attended by nurse-midwives, 87% gave birth at home.[3] Maternal mortality was .86/1000 live births,[4] neonatal deaths over these years averaged 15/1000, far below New York City rates of 28/1000 in 1931 and 18.4 in 1951.[5] In response to consumer demands, MCA established the Childbearing Center in 1975, which provides a safe alternative for families desiring a healthy birth in a nonhospital setting. The Childbearing Center is a model for care that could be replicated in rural and underserved areas of the country.[1]

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[1] 134:262
[2] 69a:4-12
[3] 82:178-184; 49:395-402
[4] 82:178-184
[5] 134:265

Madera County Nurse Midwifery Project

In 1960, the state of California funded a three-year demonstration project utilizing nurse-midwives at the obstetrically understaffed Madera County Hospital to provide prenatal care and delivery for medically indigent farmworkers. Before the project began, more than half the mothers had inadequate or no prenatal care and about one-fifth of the hospital deliveries were unattended by physicians.[2] Special waivers were obtained to employ two nurse-midwives (nurse-midwives were not legally licensed to practice in California until 1974). The midwives handled all normal cases and performed 78% of the hospital deliveries,[3] assisted by staff and consulting physicians when complications arose.

Beyond routine care, the midwives overcame "many cultural and educational barriers to motivate many more women to seek prenatal care".[4] Prior to the midwifery program, 26% of the mothers had six or more prenatal visits compared to 35% once the program opened its doors.[5] Those beginning prenatal care in the first trimester doubled from five to ten percent.[6]

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1. 48:4
2. 99:309
3. 85:51
4. 85:51
5. 99:311
6. 99:311

mothers were attended throughout the course of labor and the numbers of women returning for postpartum examinations six weeks after delivery rose from 37% prior to the project to 47%.[1]

Even more striking results are apparent when comparing rates of low birth weight and deaths before, during and after the program. During the project years from 1960-1963, low birth weight rates plummeted from 11% to 6.6%; two years after the project ended, LBW rose to 9.8%.[2] Neonatal deaths dropped from 23.9/1000 live births in 1959 to 10.3 in 1961.[3] In the three years following the departure of the midwives, neonatal mortality skyrocketed to 32.1/1000 live births, nearly one-third higher than pre-project deaths, and a tripling of project neonatal mortality. Thus, the current neonatal mortality goal of the American College of Obstetricians and Gynecologists, 10/1000 live births, was achieved twenty years ago by two midwives who provided primary care and sensitive attention to women's needs for a very high risk population.[4] Analysts of the Madera project concluded that after its closing, the decreased availability and lower quality of prenatal and delivery services accounted for the increases in LBW and neonatal mortality and the drop in prenatal care visits after the program ended.[5]

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1. 99:311
2. 85:53
3. 99:312
4. 21:166
5. 85:57

> "The main problem, therefore, is not that we lack effective preventive care techniques to assist infants, young children and pregnant women, but that techniques of known effectiveness still have not been applied widely enough." [1]

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[1] 138:23

VI. PROVIDING ADEQUATE PREVENTIVE CARE IS COST-EFFECTIVE

A. Introduction

As discussed in the previous section, various studies have clearly established the relationship between inadequate prenatal care and higher incidences of low birthweight infants.* Further, it is well-documented that low birthweight infants are significantly more likely to develop permanent disabilities such as cerebral palsy, mental retardation, learning problems, and hearing and visual disturbances.[1] Generally, this country's response to the problem of low birthweight infants has been to devote massive amounts of energy and resources to developing highly sophisticated and technological methods of saving the lives of these infants.[2] While such intervention has proven highly successful in reducing the infant mortality rates of very low birthweight babies,[3] it has also proven to be extremely costly.[4] More importantly, this approach has been aimed primarily at providing a solution to the problem -- the survival of low birthweight infants -- rather than with prevention of the problem -- preventing the incidence of such births.

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* See discussion at Section V, supra.

[1] 138
[2] 142
[3] 17:5
[4] 17

This section analyzes the costs and savings of providing adequate prenatal care to lower the incidence of low birthweight infants, as compared to the costs incurred in providing neonatal intensive care (NICU) and rehospitalization, the two most frequent and expensive types of care associated with low birthweight. While many programs have documented that increased levels of prenatal services have resulted in improved pregnancy outcomes,* none have attempted to quantify the costs and savings to the federal government that would accrue by providing prenatal care.** This petition does precisely that, using the most conservative figures and estimates available.

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* _See_ discussion at Section V, _supra_.

** Several articles have computed, simplistically, general savings to be gained by providing prenatal care to prevent the incidence of low birthweight infants. For example, one has stated that if only five women not receiving prenatal care give birth to a moderately ill premature, a very conservative estimate of the hospital cost for the five prematures would be $150,000 (not including post-hospitalization costs). However, if that $150,000 had been allocated for prenatal care, 149 women could have received prenatal care to avoid those hospital costs. M.A. Curry, _Preliminary Report on a Survey of the Access to Perinatal Care and the Incidence of Perinatal Morbidity in Oregon_ 11 (1983). This estimate, however, fails to provide evidence that caring for 149 women would save the five prematures.

Another report estimated that for 3700 women who gave birth to low birthweight infants in California, an estimated $6-$7 million would have been saved in neonatal intensive care costs had they received prenatal care. Such care for the same number of women would have cost only $2,812,000. _A Report to the Legislature, Perinatal Care Plan_ 4, Maternal and Child Health Branch, Department of Health Services, California (1982).

(footnoted continued on next page)

B. General Methodology

Generally, the cost-effective analysis in this petition surveys various health care literature and studies. In particular, the analysis relies, to a large extent, on a study conducted by Carol C. Korenbrot* on the expected costs and savings of comprehensive prenatal care to the State of California.** The study focused on the findings and conclusions of the Obstetrical Access Pilot Project, "OB Access Project", which was funded from July 1, 1979 through June 30, 1982 and

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(footnote cont'd.)

Further, a doctor is quoted as saying "Prenatal care is cheap when compared to the costs to care for an infant born in the high risk group. Care for an average premature infant that lives costs $100,000 and $60,000 for one that dies. The cost to keep an infant on a respirator for 18 months recently came to $1.5 million." G. Dallek, *America's Widening Infant Death Gap*, Health and Medicine 3 (1982), *quoting* Declaration of Dr. Sylvia Bean, filed in *C.H.A.* v. *Bd. of Supervisors*, L.A. Superior Ct., C360-546. Another doctor estimated that the cost per premature infant averages $79,418 and that every 100 women denied prenatal care will cost L.A. County $397,090 in avoidable neonatal intensive care costs. *Id.*, *citing* Testimony presented by James F. Padbury, M.D. before the Commission on the Status of Women, "Perinatal Health of Los Angeles County's Indigent Population---A Fiscal and Political Cost-Benefit Analysis", May 19, 1982.

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** Korenbrot, C., *Comprehensive Prenatal Care as MediCal Benefit, Expected Costs and Savings,* Contract Report to Maternal and Child Health, Department of Health Services, California (1982) [hereinafter Korenbrot I]. Certain parts of the study were updated in C. Korenbrot, *Additional Costs to the State for Maternal and Child Health with Public Health Block Grants* (1983) [hereinafter Korenbrot II].

registered a total of nearly 7,000 women.* The OB Access Project was designed to improve MediCal** maternal medical care in three ways: (1) increasing access to OB Access services for MediCal and low-income pregnant women in project areas; (2) assessing the quality of maternal MediCal care by review of the amount of services provided and health outcomes of patients of individual providers; and (3) to determine the impact of providing comprehensive prenatal care to project registrants.

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* The OB Access Project was formulated in response to major gaps in the availability and extent of perinatal services in California, particularly in certain geographic areas and ethnic groups. Two major problems came to the attention of state medical and health officials: (1) the inability to render adequate care at the low prevailing rate of MediCal reimbursement; and (2) MediCal eligible and low-income women were experiencing severe problems in access to physicians, particularly physicians with formal training in obstetrics.

In order to implement the project, waivers were solicited from the Department of Health and Human Services, Health Care Financing Administration. The waivers were granted under section 1115(a) of the Social Security Act for a period of three years ending June 30, 1982 (renewable annually).

In most cases the sites selected were expansions of existing community clinics and county health departments. No private providers were willing to participate as primary contractors, although they did participate as subcontractors of medical care services. This arrangement resulted in the active participation of several excellent private physicians and supervised nurse-midwives in areas where no prenatal care services had existed for MediCal and other low-income women. Preliminary Evaluation of the Obstetrical Access Pilot Project July 1979-June 1980 5-7 Maternal and Child Health Branch, Department of Health Services, California (1982).

** "MediCal" is the California equivalent of the federal Medicaid program, and means the California Medical Assistance Program. Calif. Welf. & I. Code § 14063. Under the MediCal program, federal funds match state expenditures for medical care provided under the state plan. The federal share in California is 50%.

It was the last part of the project that was under consideration in Korenbrot's analysis. That analysis was designed to determine expected MediCal savings through the provisions of comprehensive prenatal care to MediCal recipients. In the Korenbrot analysis, the prenatal care presently provided to MediCal low-income women is referred to as "present prenatal care." Korenbrot calculated the costs of present prenatal care and compared them to the cost of providing "comprehensive prenatal care".* The difference constituted the total expected cost to the state of providing complete, comprehensive care through MediCal.

Korenbrot then calculated the total expected costs to the state of caring for low birthweight infants in neonatal intensive care and in rehospitalization. In both cases, the calculations are made according to birthweight. Cost increases as birthweight decreases,** as does the frequency with which infants of different birthweights require rehospitalization and neonatal intensive care. Using the Cleveland Maternal Infant Care Study[1] as the basis for the most optimal documented effect of such a program upon birthweight, the investigation determined that a benefit-to-cost ratio of approximately 2 to 1* would accrue based upon reduction of needs for neonatal intensive care and infant rehospitalization through the first year of life alone.**

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* See discussion at 103-105, *infra*.

** See 17:5 and 94:992,998, *infra*, and discussion, p. 125.

[1] 131:150

The implications of this study are profound and provide solid evidence that prenatal care is indeed cost-effective. The analysis herein, which calculates current costs to the federal government, closely follows the Korenbrot technique. Like MediCal, the federal Medicaid program provides prenatal care to low-income Medicaid-eligible pregnant women ("present prenatal care"). The difference between the cost of providing present prenatal care and the cost of providing comprehensive prenatal care,*** multiplied by the number of Medicaid-eligible pregnant women constitutes the expected cost to the federal government for those women. The expected cost to the federal government of expanding Medicaid coverage for comprehensive prenatal care to other needy women is computed by multiplying the cost of providing comprehensive prenatal care by the number of Medicaid-ineligibles, low-income women needing such coverage. The total expected cost to the government is the sum of the costs of providing comprehensive care to both Medicaid-eligible women and Medicaid ineligibles.

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* Preliminary data show that OB Access patients had half the incidence of low birthweight compared to a matched group of Medi-Cal patients (3.9% v. 7.3%). Preliminary Evaluation at 52.

** Korenbrot I, *supra*, at 1, 12. The figures in Korenbrot I and used herein are preliminary and are based on a range of expected costs and savings predicted by calculation, rather than on actual, observed figures. At present, the actual figures are being determined by officials for the OB Access Project. Preliminary data indicate that the actual savings to the state are in fact greater than predicted in Korenbrot's analysis.

*** The cost of "present prenatal care" and "comprehensive prenatal care" are extracted from Korenbrot I, which refers specifically to "MediCal dollars." Korenbrot I at Table 2. Since the federal share in California is 50%, the federal costs are 50% of the total costs used in Korenbrot's study.

Under the Medical Assistance Program (Medicaid), Title XIX, Social Security Act, as amended; P.L. 89-97, 90-248, 91-56; 42 U.S.C. 1396 *et seq.*; P.L. 92-223, 92-603, 93-66 and 93-233, states are required to provide certain types of services for the medically needy, for which federal financial participation is available. The federal share ranges from 50% to 78%. Catalog of Federal Domestic Assistance 234, Office of Management and Budget (1983).

Costs of providing comprehensive prenatal care are then compared to the two most frequent types of current costs incurred in treating low birthweight infants -- neonatal intensive care[1] and rehospitalization.[2] It is estimated that 15%[*] of the Medicaid-eligible women receiving only present prenatal care will give birth to low birthweight infants, and that 20% of Medicaid ineligibles will deliver low birthweight infants. The total current cost to the federal government for providing care to low birthweight infants is computed by multiplying the number of low birthweight infants by the frequency of rehospitalization and NICU and by the cost of providing those services.

Finally, the initial savings to the government in providing care to reduce the number of low birthweight infants after comprehensive prenatal care is provided is computed by the same formula. Only this time the number of low birthweight infants will be much smaller since the estimates of low birth-

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1. 17
2. 94:991
* See explanatory footnote, p. 112, double asterick

weight infants will be less: i.e., 5.5%* for Medicaid eligibles and 7%* for Medicaid ineligibles. Comparing the two costs, a tremendous savings is to be gained by reducing the incidence of low birthweight infants. Moreover, even after subtracting the costs of providing comprehensive prenatal care, the real dollar savings to the government is great. Further, the savings are conservative estimates because they do not include long-term costs.

C. The Components and Costs of Prenatal Care

Comprehensive prenatal care programs were founded on the premise that the high rate of adverse pregnancy outcomes among economically disadvantaged women would be diminished by combining medical care with social, nutritional and educational services.[1] Thus, comprehensive prenatal care provides basic medical care, health education, nutrition counseling and social work counseling.[2] The components of prenatal care vary widely from state to state, hospital to hospital, and in particular they vary depending upon the needs of each individual woman. As discussed in Section V, *supra*, however, there are certain basic components of prenatal care that are essential to improving pregnancy outcome. As defined in the OB Access project and for purposes of this petition, "comprehensive prenatal care" includes routine prenatal, delivery and postpartum care (11 recommended examinations) and routine laboratory tests (22 individual tests, generally blood and urine analyses), a Psychosocial Assessment, a Nutrition Assessment, and 16 hours of Perinatal Education, as well as an initial outpatient well-baby examination. The assessments determine what interventions are indicated to reduce psychosocial nutritional or educational risks and these interventions are then 'treated' with counseling.*

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[1] 98:1
[2] 98

* See explanatory footnotes, p. 119.

Under Medicaid, state governments presently pay for prenatal care to pregnant women which differs from state to state. At the threshold, then, it is necessary to compare present prenatal care costs and comprehensive prenatal care costs to show the additional costs of adding comprehensive prenatal care to current Medicaid benefits. For example, in California, "present prenatal care", as currently provided by Medi-Cal and as defined in the Korenbrot study, includes all services in the comprehensive prenatal care package (defined above), except "assessments", 16 hours of perinatal education and vitamins. The following analysis utilizes this definition and the costs of present prenatal care as computed in Korenbrot's study.

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* For example, the OB Access Project provided health education services for "high risk behavior" such as smoking, drug abuse, alcohol abuse and non-compliance with medical advice/regimen during pregnancy to modify or change such behavior by education. Similarly, education about "high risk medical conditions" such as diabetes, blood disorders, kidney problems or second pregnancy within one year was provided by certified medical professionals. Psychosocial services consisted primarily of individual and/or group counseling or home visits to identify and treat psychosocial problems such as ambivalence or rejection of the pregnancy, spousal abuse or non-support, depression, psychotic thinking or behavior, extreme anxieties regarding labor and delivery (cesarean section, use of forceps, death, pain, baby may be abnormal). Finally, the nutritional component offered dietary, biochemical, and physical-medical education to treat mineral, protein, vitamin and other deficiencies, to prevent excessive junk food, caffeine, sugar, or fat intakes, and to treat persistent diarrhea, constipation, nausea or vomiting. Preliminary Evaluation of the OB Access Project at Appendix 3.

The costs of present prenatal care to MediCal recipients were not available directly but were estimated in two ways. A low estimate was obtained by using the "global fee" for prenatal, delivery and postnatal care of the mother, and routine care of the newborn (excluding inpatient hospital costs).[1] The total fee for a vaginal delivery with present prenatal care based on the global fee is $722.43 (1982 dollars). See Table 1 at 107. A similar estimate for a Cesarean Section with present prenatal care is $1,148.94 (including the prenatal lab fees and routine outpatient newborn examination) (1982 dollars).

A second way of estimating the costs was based on the fees-for-service for the services that should be included in present prenatal care (i.e., basic comprehensive prenatal care package excluding assessments and vitamins).[2] The expected costs shown in column 2 of Table 1 represent a high estimate of expected MediCal costs.

Comparable costs for Comprehensive Prenatal Care in the OB Access Project were higher (Table 1, columns 3 and 4). By adding all fees-for-service for the entire basic package,

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1. 81:6-7
2. 81:7

the maximum cost of a vaginal delivery is $1,111.07, including interventions or "assessments" (valued at a maximum cost of $146.41, 1982 dollars) and excluding inpatient hospital costs (1982 dollars). In computing an expected estimate for a Cesarean Section in the same way as for Present Prenatal Care above, the corresponding figure for Comprehensive Prenatal Care is $1571.83. Again, the maximum expected MediCal costs for care of prenatal, delivery and postnatal periods are shown in Table 1 under "Expected Costs" (1982 dollars).

The expected costs to the federal government of providing "comprehensive prenatal care" to pregnant women eligible for Medicaid can therefore be estimated using the figures in the Korenbrot study. Using the figures in the column entitled "Expected Costs", the additional cost to the federal government of providing comprehensive care ranges between $144.79 (50% x ($1076 - $786.41)] (low estimate in 1982 dollars) and $171.19 [50% x ($1188.01 - $845.63)] (high estimate in 1982 dollars). These figures will increase or decrease depending, of course, on the types and quantities of care currently provided by the different states under Medicaid already. Assuming that the average expected cost to the federal government is $157.99 [($171.19 + $144.79) x 1/2], and assuming that there exists approximately 396,000 women eligible for prenatal care services

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Table 1.

MediCal Reimbursement* of
Costs of Prenatal and Delivery Care
(1982 Dollars)**

	With Present Prenatal Care		With Comprehensive Prenatal Care	
	Based on Global Fee***	Based on Fees-for-services****	Based on Final Claims Claims†	Based on Fees-for Services††
Vaginal Delivery	$722.43	$776.51	$999.67	$1111.07
Cesarean Section†††	$1148.94	$1237.28	$1460.44	$1571.83
Cesarean Section Rate††††	15%	15%	16.7%	16.7%
Expected Costs	$786.41	$845.63	$1076.00	$1188.01

* Includes prenatal, delivery and routine postpartum obstetric care. Korenbrot I, supra at 22.

** All 1980 dollar figures in Korenbrot I were inflated at the medical cost inflation rate for 1981-82 of 10% per year to 1982 dollars.

*** Package rate, (8 RVS Units) with August 1980 conversion factor ($60.08/RVS Unit). 1980 was the reference year because it was the first year of the OB Acces Project registrants. But see note 25, supra. Laboratory fees and a routine outpatient newborn care examination were added to make the package comparable to the OB Access Basic Package, Table 1. Korenbrot I at 22.

**** Present Prenatal Care includes all services in Basic Package, Table 1, except "assessments" and vitamins. Comprehensive Care includes entire Basic Package.

† Not all participants in the OB Access Project utilized all comprehensive services available. During the first contract year (1980), the reported utilization rates for the Psychosocial Assessment was 84.1%, for the Nutrition Assessment, 85.2%, for the Health Education assessment 86.8%, for the Birth Edu-

(footnotes continued on next page)

under Medicaid,* the total expected additional cost to the federal government for providing comprehensive prenatal care to Medicaid-eligible women is $62,564,040.00.**

(cont'd from previous page)

cation Assessment, 72.2%. The figures in this column are thus based on observed average utilization of "assessments" with 93% of final claims for 917 registrants of the first contract year. Korenbrot I at 8, 22.

†† See note **** at 107 supra.

††† Calculated by subtracting Vaginal Delivery (4 RVS Units) from Vaginal Delivery Care costs and adding (10 RVS Units for) Cesarean Section. Korenbrot I at 22.

†††† Observed rate: 1979 MediCal Deliveries (Data Matters, #81-06011, June 1981); 1980 OB Access Pilot Project, first contract year, based on 93% final claims of 917 registrants. Id. The rates here are also consistent with the national proportion of cesarean rates to all deliveries, which was 15% in 1978. Better Health at 15.

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* Of the 3.3 million patients hospitalized for deliveries in the United States in 1977, Medicaid was expected to pay for 12 percent. Better Health for Our Children: A National Strategy, The Report of the Select Panel for the Promotion of Child Health: 1980 14, U.S. Department of Health and Human Services (1980). This figure is, of course, underrepresentative in that it has increased since 1977; it does not include those women who were not reported to be within the Medicaid system because of various state or local practices of reporting; and of the 396,000, some women will get prenatal care, others will not because even despite the availability of Medicaid, health care patterns in seeking care will not be changed. Better Management at 108.

The figure is overrepresentative of prenatal care requirements to the degree that it includes twins or triplets and it also includes women who have two children within 12 months. These occurrences, however, are still very rare.

** Average expected cost of providing comprehensive prenatal care multiplied by the number of women eligible for prenatal care services under Medicaid.

The number of women receiving early, comprehensive prenatal care would be higher if the federal government expanded Medicaid coverage to other groups of women most in need of such care ("Medicaid ineligibles"). The only existing official estimate of women needing Medicaid coverage is 220,000.*

The cost of providing comprehensive prenatal care through Medicaid to these additional 220,000 women ranges from $538 (50% x $1076) to $594 (50% x $1188.01), with an average cost of $566 per recipient.** Thus, the total expected cost to the federal government for providing comprehensive prenatal care to these women is $124,520,000.* The total expected cost to the government for providing comprehensive prenatal care to Medicaid eligibles and ineligibles is $187,084,040.**

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* H.R. Rep. No. 568, 96th Cong., 1st sess. 85 (1979). This figure is estimated from a simulation of the medicaid eligibility rules using information on income and family characteristics from the 1976 Survey of Income and Education, and was used in a cost estimate of H.R. 4962, the Child Health Assurance Act of 1979. Because the estimates were based on 1976 data, this figure is a very low estimate of the number of ineligibles.

The figure is not broken down into any specific categories of needy women. However, there are three general categories, including first-time pregnancies. Women pregnant for the first time are not universally eligible for AFDC or Medicaid's medically needy program because they have no dependent children. In 1978, 19 states had no Medicaid coverage for prenatal care for these women; in 30 states and the District of Columbia they were eligible if they met criteria of need; Arizona had no Medicaid program. *Better Health* at 9. The second category of poor pregnant women in need of Medicaid coverage are those who meet a state's income and resource standards and are now excluded from the program because, although impoverished, they are part of two-parent families. *Children's Defense Budget* at 44. Finally, the third category is composed of the women who have incomes that exceed the maximum for eligibility for AFDC but are insufficient to pay for medical care. *Better Management* at 104.

** The full cost of providing care is used here, and not the difference between present prenatal care and comprehensive prenatal costs, since these women are not now eligible under Medicaid to receive present prenatal care.

D. The Costs of Caring for Low Birthweight Infants

1. Neonatal Intensive Care

One of the primary medical expenses associated with caring for low birthweight infants is neonatal intensive care.[1] Neonatal intensive care is defined by the American Academy of Pediatrics as the constant and continuous care of the critically ill newborn.[2] This type of care consists largely of one-to-one, specialized 24-hour nursing care, respirators, blood-gas and other diagnostic and therapeutic procedures to compensate for the lack of full development of the infant.[3]

In the United States, approximately 6% of all live births (60/1000) go to intensive care (about 200,000 admissions annually).*** Nearly one half of those requiring neonatal intensive care, or 100,000 are due to complications associated with low birthweight.[4] The costs of neonatal intensive care are great. One study has concluded that among patients with high hospitalization cost ($4,000 or more in one year), neonatal cases were by far the most expensive, averaging over $20,000 each.[1] Various reports of neonatal intensive care costs range from $1,800 to $40,000 per patient.[2] Neonatal intensive care costs vary greatly according to a variety of factors, including low birthweight. Studies have shown that as birthweight decreases, cost increases.[3] Average expenditures in 1983 per patient are estimated to be about $13,400.* The total annual costs in the United States for low birthweight-related neonatal intensive care is therefore approximately $2.6 billion.** For low birthweight-related neonatal intensive care, costs are one-half that, or $1.3 billion.***

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* Average cost of comprehensive prenatal care multiplied by number of women requiring Medicaid coverage.

** Total expected cost of providing comprehensive prenatal care to Medicaid-eligible women added to total expected cost of providing comprehensive prenatal care to women requiring Medicaid coverage.

*** Budetti at 7. This is an estimate of neonatal intensive care units admissions available in the literature and from NICUs. No national data exist that describe the amount of neonatal intensive care currently being delivered in the U.S.

[1] 17:11
[2] 17:7
[3] 17:7
[4] 16

The federal share of providing neonatal intensive care is difficult to ascertain, since there are only minimal data regarding how much of the cost is paid for by Medicaid.[4] It is known, however, that approximately 396,000 women per year obtain present prenatal care through Medicaid.* From this number of women, it is conservatively estimated that approximately 15%**or 59,400 will give birth to low birthweight infants.[51] It is also estimated that of the 220,000 Medicaid ineligibles, 180,000 will be covered by Medicaid once they give birth***, and 20% or 36,000 will deliver low birthweight infants.**** Of the 59,400, approximately 25% or 14,850 will be very low birthweight infants (1500 gms or less); the remainder, 44,550 will be low birthweight infants weighing 1501 to 2500 grams. Of the 36,000 ineligibles, approximately 30% or 10,800 will be very low birthweight infants; the remainder, 25,200 will be low birthweight.[*]

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* Speech by Peter Budetti. See also Budetti at 5 (estimated average expenditures per patient to be about $8,000 in 1978). The estimate cited in the text is an updated figure.

** Number of births (3.3 million) multiplied by percentage of all low birthweight births admitted to NICUs (0.06) multiplied by mean cost/patient ($13,400).

*** See note **, supra.

[1] 17:19
[2] 17
[3] 17:5
[4] 17:23-27

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* See note *, at 108, and accompanying text.

** Since there are no data regarding the number of low-income women (both Medicaid eligible and Medicaid ineligible) who deliver low birthweight infants, the 15% figure was estimated from a review of the low birthweight rate of low-income women throughout the country. For instance,in the Cleveland study,the low birthweight rate was 14%. Sokol, et al. at 155. In Minnesota the rate was 13.9%. Berg, et al. at 33. In rural Georgia, 24%. Reid and Morris at 491. In New York City, 21.9%. Gold, et al at 1951. In the South Bronx, 18.1%. Doyle and Widhalm at 4. In California, 7.3%. Prel. Evaluation of the OB Access Project at 52. Thus, the 15% estimate is within the range of previously reported low birthweight rates among low-income women.

*** Of the total 220,000 Medicaid ineligibles, 60,000 are first-time pregnancies who will be covered by Medicaid once they deliver. See H.R. Rep. No. 568, 96th Cong., 1st sess. 86 (1979). Of the remaining 160,000, 80,000 will also be covered by Medicaid as "financially needy" children (commonly known as "Ribicoff" children after the Senate sponsor of the 1965 Medicaid amendment creating this eligibility category). Because the original 220,000 ineligibles in based on an estimate of those women whose incomes are less than 80% of the poverty level, id., 80,000 is a fair estimate of "Ribicoff" children, whose family incomes are between 40%-50% of the poverty level. Finally, the remaining 40,000 will be covered as "medically needy" children under the Medicaid program.

**** The 20% figure is estimated from 15%, see note **, supra, and increased to account for the fact that these women are low-income who receive little or no prenatal care (as compared to the Medicaid eligibles who receive present prenatal care) and who will therefore fare worse than those receiving such care.

Table 2 shows the current federal costs of neonatal intensive care for low-income, low birthweight infants.

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[*] Of the 3.3 million total births annually, 7% or 230,000 are low birthweight infants (2500 gms or less). National Center for Health Statistics, *Monthly Vital Statistics Report, Final Natality Statistics*, 1975-1980 HEW. 16% of those low birthweight infants are very low birthweight. That percentage is increased here to 25% for Medicaid eligibles and 30% for Medicaid ineligibles to account for the fact that the very low birthweight rate among Black, low-income women is two to three times the rate for whites, Budetti at 13, and the fact that the Medicaid ineligibles are at a higher risk of delivering very low birthweight infants because they receive little or virtually no prenatal care. Further, these percentages reflect a very small portion of the total group of eligibles and ineligibles.

Table 2.

Federal Costs of Neonatal Intensive Care of Low Birthweight Infants

Birthwgt. (gms)	Freq.* (%)	No. of LBW infants** (95,400)	Infants requiring NICU***	Cost/ infant† ($)	Total Cost†† ($)
≤1500	100	25,650	25,650	20,720	531,468,000
1501-2500	32.8	69,750	22,878	2,090	47,815,020
				TOTAL:	$579,283,020

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* This column represents the frequency with which infants in the various low birthweight categories require intensive care. The 32.8% figure constitutes a weighted average of the frequency percentages for birthweights 1501-2000 (85%) and 2001-1500 (21%). Korenbrot II at Appendix B.

** See discussion at 112-113, supra.

*** The figures in this column are obtained by multiplying the number of low birthweight infants by birthweight with the frequency percentage.

† Korenbrot II at Appendix B (1982 dollars). The $2090 figure is the average cost for those infants weighing 1501-2000 ($2560) and 2001-2500 ($1620). Id.

†† Number of infants multiplied by cost per infant.

2. Rehospitalization in the First Year of Life

Generally, the first year of life is an age when morbidity and medical use are high, and this is particularly true for low birthweight infants.[1] It is not surprising, then, that another major medical expense associated with caring for low birthweight infants is rehospitalization. "Rehospitalization," as used herein, is defined as one or more events of hospitalization of an infant during the first year, not including the hospitalization after birth before the infant went home for the first time.[2]

In a study of the rehospitalization of infants,** information on health problems, medical care utilization, and developmental status was obtained from a large random sample of 4,989 infants born to residents of eight regions during a six-month period in 1976.* Using these data, it was found that 9.1% of the total had been rehospitalized at least once during the first year.[3] This is within the range of previously reported values which may vary from 7.0% of infants of affluent families to 20.0% of those in disadvantaged settings.[1] Low birthweight infants were over twice as likely and very low birthweight infants 4.5 times as likely to be hospitalized as normal birthweight infants.[2] Further, the percentage rehospitalized increased with decreasing birthweight; 38.2% of infants, 1,500 grams or less experienced at least one hospitalization during the first year.[3] Low birthweight infants also accrued more hospital days.[4] Hospitalized infants with birth weights over 2,500 grams averaged 7.8 days in the hospital, but this figure increased to about 16 days for those 2,000 grams or less at birth.[5] Thus, although low birthweight infants accounted for 6.4% of surviving one year old infants, they accounted for 13.6% of those hospitalized and 20.0% of all hospital days among this group of infants.[6] See Table 3.

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* The eight regions, characterized by a wide spectrum of ethnic and sociodemographic variables and medical care environments, accounted for about 6% of the births in the U.S. They were: State of Arizona; 15 counties around Syracuse, in Upstate New York; upper west-side of Manahattan (Central Harlem, Washington Heights, Riverside); Dallas County; Cleveland and surrounding Cuyahoga County; three regions in Los Angeles County (Southeastern, Central and Coastal Regions and San Gabriel Valley).

** See 94:7 (the "McCormick study")

[1] 94:991
[2] 94:992
[3] 94:992

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[1] See 94:998; 58:644; 1:425; 66:425
[2] 94:992, 998
[3] 94:992, 998
[4] 94:992, 998
[5] 94:992, 998
[6] 94:992, 998

Table 3.

Percentage Rehospitalized, Average Days of Hospitalization for Low Birthweight Infants[1]

	Birth Weight				
	≤1500	1501-2000	2001-2500	≤2500	≥2500
Total: 4,989	259	660	2,260	3,179	1,777
% Rehospitalized at least once	38.2	21.0	16.2	19.0	8.4
% Rehospitalized who were rehospitalized more than once during first year	34.7	39.0	25.5	----	16.5

Reasons for rehospitalization were similar for all birth weight groups, and only a small set of conditions accounted for the majority of admissions.*

Using the average number of days for each infant rehospitalized by birthweight, the average cost per infant according to birthweight, and the total number of low birthweight infants delivered by both Medicaid eligibles and ineligibles,** the

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* The reasons for admission included congenital anomaly/developmental delay, lower respiratory and upper respiratory tracts, GI tract, accident/ingestions, and other infections. _Id_.

** _See_ discussion at 112-13, _supra_.

1. 94:993 Table I

current costs to the federal government are calculated as follows:

Table 4.

Federal Costs of Rehospitalization for Low Birthweight Infants

Birthwt. (gms)	ALOS* (days)	No. of infants** (95,400)	Frequency† (%)	Infants rehosp.††	Cost/ infant††† ($)	Total cost ($)
≤1500	16.2	25,650	38.2	9,798	3,920	38,408,160
1501-2500	12.5	69,750	19.0	13,252	1,560	20,673,120
					TOTAL:	$59,081,280

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* Average length of stay. McCormick, et al. at 993, Table 1.

** *See* note *, at 112-13 and accompanying text.

† This column represents the frequency with which infants in the various low birthweight categories require rehospitalization. Korenbrot II at Appendix B.

†† Frequency percentage multiplied by the number of infants.

††† Korenbrot II at Appendix B. It is important to note that these cost estimates refer to federal dollars only. The total Medi-Cal expenses (state and federal) would be double the figures in the text.

Taken together, the current costs of rehospitalization and neonatal intensive care for low birthweight infants is $638,364,300. This sum is compared to the initial savings to the federal government for providing such care with the reduction of low birthweight; that is, those low birthweight infants remaining even after comprehensive prenatal coverage. It is estimated that if comprehensive prenatal care is provided to the 396,000 Medicaid eligibles, 5.5% or 21,780 will deliver low birthweight infants. Of the 21,780, 7% or 1,524 will be very low birthweight; the remainder, 20,256 will be low birthweight.*

It is also estimated that if comprehensive prenatal care is provided to the 180,000 Medicaid ineligibles who are covered by Medicaid once they give birth, 7% or 12,600 will be low birthweight. Of the 12,600, 9% or 1,134 will be very low birthweight; the remainder, 11,466 will be low birthweight.**

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* The 5.5% figure was estimated from a review of the low birthweight rate of low-income women throughout the country who had had comprehensive prenatal care coverage. In Oakland, California, 3% (3:1-2). In Minnesota the rate was 5:5% (6:33). In rural Texas, 4.4.% (109:26). In the South Bronx, 6.3% (44.32). In California, 3.9% (91:52-59).

** The 7% figure was also estimated from the studies in note *, supra.

The expected cost to the government is thus computed as follows:

Table 5.

Expected Costs to the Federal Government
for Care of LBW Infants after Comprehensive Prenatal Care

NICU Costs

Birth-weight (gms)	Freq. (%)	No. of LBW infants (34,380)	Infants requiring NICU	Cost/ infant ($)	Total Cost ($)
1500	100	2,638	2,658	20,720	55,073,760
1501-2500	32.8	31,722	10,404	2,090	21,744,360
					$76,818,120

Rehospitalization Costs

Birth-weight (gms)	Freq. (%)	No. of LBW infants (34,380)	Infants/ rehosp.	Cost/ infant ($)	Total Cost ($)
1500	38.2	2,658	1,015	3,920	3,978,800
1501-2500	19	31,722	6,027	1,560	9,402,120
					$13,380,920
				TOTAL:	$90,199,040

In summary, the current cost of providing NICU and rehospitalization for low birthweight infants is $638,364,300, as compared to the expected cost of providing such care with the reduced incidence of low birthweight resulting from comprehensive prenatal care coverage, $90,199,040. This is obviously a tremendous savings, given the great disparity of costs, and results in an initial savings of $548,165,260, ($638,364,300 - $90,199,040). After subtracting the costs of providing comprehensive prenatal care, $187,084,040, the resultant real dollar savings to the federal government is $361,081,220.

The foregoing cost for providing comprehensive prenatal care can probably be decreased with the use of nurse-midwives instead of physicians in both prenatal care and delivery. On the other side of the equation, the current cost of providing NICU and rehospitalization is a very low figure considering the conservative estimates that 15% of the Medicaid eligibles and 20% of the Medicaid ineligibles will deliver low birthweight infants.

Further, the estimates for both NICU and rehospitalization include only Medicaid costs. Other federal programs which pay for both intensive care and rehospitalization include the Crippled Children's program and the MCH program. The MCH program alone provided a total of $7 million, or 11% of its total budget, for neonatal intensive care in 1978.* Finally, the federal dollar figure does not include the long-term costs such as treatment and institutionalization for physical and mental disabilities not requiring hospitalization that are more frequently associated with low birthweight.**

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* Better Management at Appendix I.

** For example, the lifetime costs of care for developmentally disabled individuals has been estimated to be between one-half and $6 million per individual, based on institutional costs of $20,000 a year with an average life of 40 years. 129 Cong. Rec. (Sen. Cranston) (daily ed. Jan. 26, 1983).

E. Other Long-Term Costs

The preceding section demonstrated the cost-effectiveness of providing preventive, prenatal care as compared to providing only two types of costly treatment for low birthweight infants. There exist, however, several other long-term costs to the infant, its family, and to society as a whole that are associated with low birthweight, which further strengthen the cost-effectiveness argument. Various studies have shown that while there has been an improvement in the prognosis for life and normal development for low birthweight infants since the 1960s, the incidence of both major and minor handicaps is still high.[1]

1. Developmental Delay/Congenital Anomalies

Low birthweight has been directly correlated with a high risk of severe impairment and severe developmental delay.* In a follow-up of the McCormick study,** data was collected to measure the incidence of delay/congenital anomalies among surviving infants at the end of the first year of life.[2] Results of the study showed that from a total of 4,377 infants, 14.3% of very low birthweight infants (less than 1500 gms) were severely impaired, compared to 1.6% of normal birthweight infants (more than 2500 gms).[1]

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* Shapiro, et al., Correlates of Death and Morbidity at One Year of Age, 136 Am. J. Obstet. gyn. 363 (1980). Severe impairment includes congenital anomalies such as mental retardation, Down's Syndrome, major cardiac malformations, congential cataracts, and cystic fibrosis. Moderate impairment includes cleft palate, clubfoot, and hypospadias (urethra open externally-down midline).

Severe developmental delay is based on an exam of gross and fine motor activities (scoring less than 70) and other developmental indices. An example is cerebral palsy.

** See 94:991

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[1] 38:85
[2] 124:363

Depending on the severity of impairment, both federal and state governments incur major expenses caring for the medical and nonmedical needs of the developmentally disabled, such as expenses of institutionalization, generic services, and special education, of the developmentally disabled. For institutionalized care alone, it has been estimated that approximately $315,250 will be incurred per case (1982 dollars).*

All levels of developmental disability (severe, moderate, or mild) can be influenced by prenatal care and birthweight.[2] The many and varied costs of treating and caring for developmentally disabled persons can thus be avoided by preventing the incidence of low birthweight through comprehensive prenatal care.

2. Physical Handicaps

Among the most common types of physical handicaps suffered by low birthweight infants are blindness, deafness, and major and minor birth defects.[1] Recently, incidences of moderate to severe deafness of 1-1.8% have been reported in very low birthweight infants.[2] Blindness seems to be the most predominant of physical handicaps.* In one study, the author estimated that in 1979, 546 infants were blinded from retinopathy of prematurity (retrolental fibroplasia) in the U.S.[3] Blindness results from oxygen being applied to resuscitate and maintain premature infants of low birthweight during the neonatal period.** The blood vessels in the retina constrict in response to a certain dose of oxygen and bleeding and tissue injury result in scarring (cicatricial disease) which may progress to cause blindness.***

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* Korenbrot II at Appendix B. This estimate is based on the present value of 20 years of institutionalized care for 95% of the severely delayed and generic services for the other 5% not institutionalized. Costs of care in the future were discounted at the State Treasurer's Portfolio rate of interest of 10% per year. Id.

It should be noted that "severely developmentally delayed" as defined in Korenbrot II differs from the definition used in Shapiro, et al. In Shapiro, severe impairment included congenital anomalies other than mental retardation which may not warrant institutionalization, whereas Korenbrot focuses solely on developmental disabilities requiring institutionalization, which accounts for the 95% rate of institutionalization. Korenbrot II at 5.

[1] 124
[2] 94

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* Of 7% of low birthweight infants who had insoluble physical problems, 6% had blindness. Koops at 349.

** *Id.* Apart from retrolental fibroplasia, there are several other potential long-term hazards of certain intervention techniques used in neonatal intensive care, adding to the costs associated with low birthweight. Infants undergoing phototherapy have been found to suffer from lactose intolerance, diarrhea, skin rashes, and dehydration. *Deepening Crisis in Health Care* at 144. Environmental hazards with the intensive care nursery such as emission of vinyl chloride gas, exposure to microcurrents and radiation from portable x-ray units are dangerous to infants. *Id.* Other hazards include radiant heaters, alkali therapy, high noise level of incubators, and arterial catheterization. *Id.* *See also* Stavis, R., Kraus A., *Neonatal Intensive Care*, *Clinics in Perinatalogy* (Mar. 1980).

*** Phelps at 925. This occurs primarily to very low birthweight infants (less than 1500 grams). According to Phelps, there is insufficient information about the amount of oxygen which will cause blindness, and very often these infants often stop breathing or require respirators neonatally, necesitating use of substantial amounts of oxygen.

1. 80:87
2. 38:87
3. 111

The cost of treating and caring for the blind, the deaf, and those with birth defects that affect their productivity is difficult to calculate, but is certainly one of the costs associated with low birthweight. Of importance is the fact that Phelps, author of the aforementioned study, emphasizes that the number of cases of blindness in these infants will continue to rise until prematurity and low birthweight can be prevented. since this disorder is caused first by prematurity and only secondarily by oxygen.[1]

3. Learning Disabilities

Infants with low birthweight tend to have difficulty in school.[2] School failures have been noted in 30% of ten year old children of normal intelligence with a birthweight of less than 1500 grams.[3] The consensus of opinion from the older surveys leaves no doubt that the low birthweight child and particularly the very low birthweight child was at considerable disadvantage in the school classroom, even when no clinically detected handicap was present.[4]

A delay in speech development in low birthweight infants has also been documented.[5] In testing 96 infants at five years of age, researchers found that 33% of the boys and 26% of the girls had delayed onset of speech. At school age 31% of the boys and 18% of the girls had severe speech defects which included both receptive and expressive parameters of language. The normal

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1. 111
2. 22
3. 22
4. 38:88
5. 80:346

school population had a 1.5% incidence of speech defects. School performance of 50% of the boys and 36% of the girls was not satisfactory.[1]

The costs of providing special education, testing, and medical treatment to improve or overcome learning disabilities are thus another long-term cost associated with low birthweight.

4. Intangibles

Low birthweight also produces several other adverse outcomes which result in less tangible costs, but which must nonetheless be included in the aggregate costs to the infant, its parents, and society in general.* For example, studies have revealed that low birthweight infants who require neonatal intensive care have the lowest interaction with mothers with weak social support systems.** These mothers visited least, touched least, and were least concerned about the development of their offspring.[2] This creates the potential for serious long-term relationship problems between mother and child. Similarly, because low birthweight infants are twice as likely to be rehospitalized than normal birthweight infants,*** they must be separated from their parents for extended periods. This physical separation prevents the normal parent-infant interaction in the earliest days of life which has been found not only to shape behavioral patterns, but the electrochemical circuits of the thinking process as well.[1]

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* The following is an illustrative list of problems reportedly associated with low birthweight. It is not intended to be an exhaustive list of long-term problems since they are not fully known.

** High-Risk Follow Up at 3. This included families where the fathers were abusive, had abandoned the family, or the couple were in the process of separation.

*** See discussion at 117-119, supra.

1. 80
2. 22:4

A few studies report the correlation of low birthweight to child abuse. One study showed that low birthweight babies comprise 23.5% of reported child abuse of children who are less than one year of age. Among the factors precipitating such abuse were biologically impaired infants, limited parent-infant contact during the nursery period, and stress resulting from limited resources to care for the infant.[2] Another study found that of 255 infants discharged from a regional newborn intensive care unit to their parents, ten (or 3.9%) were subsequently reported as victims of maltreatment during the first year of life. Some of the family psychosocial characteristics significantly associated with the maltreatment included social isolation, family history of child abuse and neglect, inadequate child care arrangements, and serious marital problems. Maltreated infants were less mature at birth and had more congenital defects than their nursery mates. Finally, there was less family-infant contact during the prolonged nursery hospitalization in families in which maltreatment eventually occurred.[3]

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1. 22:4, 39:109
2. 22:4, 74:15
3. 69:629

Other emotional problems include the stress and strain of caring continuously for the infant; the shock of having to cope with an abnormal birth; prolonged parenting demands with little responsiveness from the infant; and atypical sleep-wake cycles.[1] How does one measure the "cost" of being normal or the diminished quality of parenting experience? Further, how does one measure the "cost" of trauma suffered by a family that must witness a neonatal intensive care episode? Thus, an incalculable cost is the tremendous human suffering that occurs from care and treatment of a low birthweight infant.

In the end, the financial costs are ultimately borne by society. Even mild impairment resulting from low birthweight may affect the lifetime productivity of a person, necessitating dependency on unemployment or welfare stipends. Also, many families burdened with large hospital bills may themselves be forced to enroll for welfare. These costs are wasteful and unnecessary, especially when it is clear that they can be substantially reduced through prenatal care.

F. Efforts to Reduce the Incidence of Low Birthweight Have Been Stymied by Federal Program Cutbacks in the Reagan Administration.

Many federal programs and services aid in reducing the incidence of low birthweight, and, in turn, reducing the federal costs of caring for low birthweight-associated illnesses and long-term problems. Yet despite their proven success rate and cost-effectiveness, the Reagan administration is determined to reduce federal spending or eliminate altogether these programs. The administration's policy is not simply foolish; it is disastrous. Any savings to be gained by cutting these programs will soon be consumed by the tremendous costs relating to low birthweight that the government will ultimately pay.

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[1] 22:3-5

The most disastrous cutbacks and regressive changes in federal programs include the following:

- not allowing federal AFDC assistance to mothers pregnant for the first time until their sixth month of pregnancy. Previously, states could claim federal reimbursement for AFDC for these mothers from the time the pregnancy was medically confirmed. Half the states did so. In addition, in many states federal assistance is no longer provided for medical benefits for the unborn child. Therefore, women pregnant for the first time have not only lost AFDC benefits, but also essential medical care.*

- for hundreds of thousands of pregnant women the Medicaid program pays for prenatal care and delivery services. Although the Reagan Administration proposed cutting a total of $11.7 billion out of Medicaid over four years, Congress passed $3.1 billion in Medicaid cuts in FYs 1982, 1983, and 1984 under the Omnibus Reconciliation Act of 1981. For FYs 1984, 1985, and

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* *Children's Defense Budget* at 82. A large proportion of first-time pregnancies are due to teenagers and unmarried women. In 1977, when 7.1% of the babies weighed 2500 grams or less at birth, 11% of the babies born to adolescents under 18 years were low birthweight babies. *Better Health* at 8. In 1975, the proportion of low birthweight infants among babies born to unmarried women was about twice as high as the proportion among babies born to married women (12.9% v. 6.5%). *Id.* at 17. There is some overlap, in that half of all births to unmarried women are to teenagers, *id.*, but the incidence of low birthweight infants among these two groups is still above the national average. Denying benefits to first-time pregnant women will therefore result in an increased incidence of low birthweight infants who, as discussed earlier, will require greater costs in long-term care.

1986, the Administration has proposed cutting an additional $1.9 billion.*

- despite several Administration proposals to terminate WIC as a separate program and merge it into the Maternal and Child Health Block Grant, WIC is one of the few programs that has managed to escape budget cuts to date. However, WIC is still not free from further attacks. The Administration's FY 1984 budget proposes to hold the WIC program at the same funding level as in FY 1983 without any provision for inflation or rising costs to the program and despite the hundreds of thousands of women, infants, and children on waiting lists for this program.**

- in FY 1982 and FY 1983, the Administration proposed abolishing the Community and Migrant Health Centers and Family Planning Programs and replacing them with block grants at decreased funding levels. Presently, both programs are operating at FY 1982 funding levels. For FY 1984 the Administration has proposed freezing funding for the programs and again trying to include them in a block grant.***

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* *Children's Defense Budget* at 68, 78. In the decade before Medicaid, infant mortality rates changed very little. Following enactment of Medicaid, infant mortality rates fell sharply: from 25 deaths per 1,000 live births in 1965 to 13 deaths per 1,000 live births in 1979. Maternal mortality rates have also dropped significantly. *Id.* at 67. While many factors may have contributed to the decline in rates, it is certain that Medicaid played a large role by making coverage of prenatal care and delivery accessible to the poor.

** *Children's Defense Budget* at 130. WIC is one of the most successful of all federal programs. A study conducted at the Harvard School of Public Health found that WIC caused a marked reduction in the incidence of low birthweight infants. It also found that, because of the reduced incidence of low birthweight infants needing extended hospital care after birth, each $1 spent in the prenatal component of WIC actually averted $3 in hospital costs. *Id.*

*** *Children's Defense Budget* at 70. In 1981, 827 community health centers provided comprehensive care in the most medically underserved urban and rural areas of the nation. In addition, some 128 migrant health centers reached families in the migrant stream--a population in which almost 20% of women, four times the national average, receive little or no prenatal care, and in which nearly half of all women have experienced at least one out-of-hospital birth. Studies have shown that community and migrant health centers deliver care that is high quality and cost-effective, and can reduce hospitalization rates between 25% and 44%. *Id.* (footnote continued on next page)

- devastating cuts in AFDC took effect in FY 1982 and FY 1983. The Omnibus Budget Reconciliation Act of 1981 slashed the federal AFDC program by slightly over $1 billion for FY 1981. Combined with a resulting loss in state matching funds, this constitutes a total AFDC cut of almost $2 billion. Then the Tax Equity and Fiscal Responsibility act of 1982 cut federal expenditures for AFDC by an additional $85 million for FY 1983.*

- the Maternal and Child Health Block Grant** was created and funded in FY 1982 at $373 million, an 18% cut from 1981 appropriation levels. The MCH Block Grant's FY 1983 funding is frozen at the FY 1982 level and the Administration intends to maintain this level for FY 1984.***

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(footnote cont'd.)

During 1981 over 4.5 million young women and mothers received family planning and health education services at about 5,000 family planning sites nationwide. In addition to delivering important health services, the programs yield a documented savings of $1.80 for every $1.00 invested. Id.

* Children's Defense Budget at 81. Welfare administrators report that 10 to 25 percent of the families that lost AFDC due to FY 1982 cuts subsequently had to return to AFDC support. Many of these families previously had received only partial AFDC grants due to earned income, and returned to the rolls when they lost jobs. Id. at 85.

** This block grant, which has been implemented by all 50 states, combined the previous Title V program, see note 106, infra, with six other specialized programs---Sudden Infant Death Syndrome, Lead Paint Poisoning Prevention, Genetic Screening, Hemophilia Treatment, Adolescent Pregnancy Services, and Supplemental Security Income Rehabilitation Services for Disabled Children. Id. at 69.

*** Children's Defense Budget at 69. In 1980 the Title V Maternal and Child Health and Crippled Children's Program reached nearly 12 million children and mothers with services ranging from basic prenatal care, checkups, and immunizations to the most sophisticated types of medical care for high-risk newborns and children suffering from handicapping conditions.

The two most common justifications for these cutbacks and changes are (1) to save the government money and (2) the states will provide a "safety net" to fill in the gaps left by billions of federal social program cutbacks. The foregoing discussion on the comparative costs of prenatal care and low birthweight-related expenses clearly shows that even if the government saves some money by cutting back on these programs, in the long run the government will spend much more to treat the conditions it has created.

The second justification is a myth. In fact, most states are neither willing nor able to replace the services and programs provided by the federal government. Many of the states' anticipated year-end balances for FY 1983 show either substantial deficits or no balances at all.[1] Every state has reduced its Medicaid program for mothers and children by cutting back on services or making eligibility more difficult to obtain or both.[2] Forty-seven states reported cutbacks in the Title V Maternal and Child Health Block Grant program through restrictions in eligibility and/or services.[3] In 1982 human services officials from 55 cities nationwide ranked health care programs as the most common area affected by federal budget cuts.[4] With fewer federal and state dollars to administer these programs, it takes no stretch of the imagination to realize that state and local governments will shift program support from preventive care to crisis acute care, since preventive care is elective, acute care necessary.* The Reagan Administration is therefore engaging in wishful thinking to suppose that the states will fill in the gaps left by federal cuts.

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[1] 29:34
[2] 29:74
[3] 29:75
[4] 29:68

In summary, it is ironic that the Reagan Administration perseveres in its efforts to reduce federal spending in programs and services that have proven to be successful and cost-effective. These reductions leave many women and children without access to care and at increased risk of illness, disability, and death, the cost of which will ultimately be borne by the federal government.

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* Korenbrot II at 1.

VII. REJECTING THE SURGEON GENERAL'S, THE COMPTROLLER GENERAL'S AND THE SELECT COMMITTEE'S 1980 CONCLUSIONS ON MATERNAL AND CHILD HEALTH, THE CURRENT ADMINISTRATION SETS POLICIES DESTINED TO INCREASE INFANT MORTALITY AMONG THE POOR, AMONG MINORITIES.

The federal government was thrice told in 1980 by such authorities as the Comptroller General, the Surgeon General, and Congress' Select Panel for the Promotion of Child Health that the nation's capacity to reduce the infant mortality rate and the racial infant death gap was easily in grasp. The current administration, coming in on the heels of these findings and blinded by its unique philosophical predilictions, nonetheless discarded these conclusions and, in the process, discarded the lives of hundreds of babies, mostly poor and mostly Black.

In January 1980, the Comptroller General reported to Congress on: *Better Management and More Resources Needed to Strengthen Federal Efforts to Improve Pregnancy Outcome*. Shortly thereafter, in the Fall of 1980, the Surgeon General issued *Promoting Health/Preventing Disease* which established health goals for 1990 with very specific objectives for pregnancy and infant health. The Reagan Administration has formally embraced these objectives, including the goal of reducing infant mortality to 9/1000 by 1990.[1] Finally, in December 1980, the Select Panel for the Promotion of Child Health

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1. 11

issued three volumes entitled: Better Health for Our Children: A National Strategy.

Each report focuses on the United States' relatively high overall infant mortality rate, on the racial death gap, and on low birth weight as the primary target if the prospects for infant survival, especially for minority infants, are to be improved. Each sets forth the same solutions and the same priority: access to comprehensive prenatal care for all poor, pregnant women.

Specifically, after surveying many experts and state authorities, the Comptroller General reported its findings:

> "Women who receive inadequate prenatal care are most likely to have underweight babies (a characteristic associated with nearly two-thirds of infant deaths), although other facts (such as mother's age, education, socioeconomic level, etc.) also influence pregnancy outcome. Although it is not always known which factor has the greatest influence, authorities continually stress the critical nature of prenatal care. State MCH directors responding to our questionnaire indicated that expanding or improving prenatal care services was their highest priority for improving pregnancy outcome. Also, according to BCHS [Bureau of Community Health Services],
>
> > 'Few health activities have as much potential for promoting health at crucial points in the life cycle. While project may find the delivery of these services expensive, their effective provision can ultimately reduce some health care costs and can greatly improve the quality of life for many patients. [Emphasis supplied.] [1]

The Comptroller General then proceeds to describe the specific changes and improvements necessary if federal programs are to

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1. 142:83

insure adequate prenatal care for all poor, pregnant women. The list is not new; quite the contrary, it reads like a well-worn litany whose words have been repeated so often they are, apparently, no longer heard. While "preventive care" may lack the catchy ring of "new federalism" or "right to life," preventive care is the known solution to the primary condition associated with infant mortality: low birthweight. Solicitous sentiments are no substitute for real solutions.

Similarly, the Surgeon General described the same problem and prescribed the same solution, *i.e.*, prenatal care:

> "Assuring all infants a healthy start in life and enhancing the health of their mothers are among the highest priorities in preventing disease and promoting health. The principal threats to infant health are problems associated with low birth weight and birth defects which can lead to lifelong handicapping conditions. Of particular concern are the disparities in the health of mothers and infants that exist between different population groups in this country. These differences are associated with a variety of factors, including those related to the health of the mother before and during pregnancy as well as parental socioeconomic status and lifestyle characteristics. Although the precise relationship between specific health services and the health status of pregnant women and their infants is not certain, the provision of high quality prenatal, obstetrical, and neonatal care, and preventive services during the first year of life, can reduce a newborn's risk of illness and death. Of particular concern are adolescents, whose infants experience a high degree of low birth weight and whose health problems should be addressed in broad context taking into consideration social and psychological implications."[1] [Emphasis supplied.]

The Surgeon General then set health goals for 1990. They include reducing infant mortality to 9/1000 for the entire population and for the minority population to 12/1000. The latter, if achieved, would reduce the current rate for miniorities by 50% and, in many localities, by 100% or more. While the Reagan Administration has formally adopted these goals, it has repudiated the only recognized means of reaching these same objectives. Specifically, the Surgeon General recommended as a "strong priority":

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[1] 139:15

> "-- early and continuing prenatal care, particularly for those at greatest risk--poor, poorly educated women, those near the beginning or the end of their reproductive age, those with previous pregnancy loss and those with recent pregnancy;
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> * * *
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> -- systems of care that reach everyone with basic services, emphasizing advantageous personal health, behavior and including outreach, education, and easy access to community-based services without social, economic, ethnic or time or distance barriers."[1]

Yet, the current administration has dismantled or destroyed the very federal health programs which could have fulfilled these objectives. (See discussion *supra*, pp. 128 - 133) In their place, the Reagan Administration offers the "volunteerism" of 50 organizations who have launched a "Healthy Mothers/ Healthy Babies" campaign, albeit well intended:

> "-- To supply information that encourages healthy habits for pregnant women and women planning pregnancy.
>
> -- To motivate pregnant women to protect their health through regular prenatal care and good nutrition."[2]

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1. 139:15
2. 88:2

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Encouraging women to seek prenatal care when none is available is a futile exercise which, given the devastating consequences of little or no prenatal care, borders on the sadistic. Yet, this "private-public initiative"[1] constitutes the entire Reagan effort to reduce infant mortality and to achieve the Surgeon General's 1990 goal.

Finally, in late 1980, the Select Panel for the Promotion of Child Health delivered its three volume report to Congress and DHS. The panel's mandate was to examine the state of "children's and expectant mothers" health, and to recommend legislative and administrative action where necessary to improve the national health profile. In its first chapter identifying "major concerns," the panel stated the case for widespread access to comprehensive prenatal care:

> "The potential benefits of preventive care and health promotion are especially great for mothers and young children... The main problem, therefore, is not that we lack effective preventive care techniques to assist infants, young children, and pregnant women, but that techniques of known effectiveness still have not been applied widely enough... Prenatal care is clearly related to positive pregnancy outcome. Many of the risks associated with low birth weight can be identified in a first prenatal visit, and steps can be taken to prevent or correct them. Conversely, late care or no care is associated with low birth weight, increased prematurity rates, increased stillbirths, and increased newborn mortality. A pregnant woman who receives no prenatal care is three times as likely as others to have a low birth weight baby (one weighing less than 2,500 grams, or about 5.5 pounds). In 1977, neonatal, post-neonatal, and infant death rates were four times higher

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[1] 9:503

> for babies born to women who received no prenatal care than for those receiving at least some care. [footnote deleted.]
>
> Despite the effectiveness of timely prenatal care, almost 10% of all pregnant women receive none at all or only belated (third trimester) care. These percentages are significantly higher among poor, black, adolescent, and unmarried women, those in rural areas, and those over 35--the very groups most likely to be at high risk from other causes."[1] [Emphasis supplied.]

The remedies petitioners seek are, in great part, an updated version of the Select Panel's recommendations. Petitioners' proposals are, if anything, more modest insofar as petitioners emphasize administrative decisions tailored to the current structure and funding of federal health programs, rather than seeking legislative changes.

The goals, then, of the Select Committee, the Surgeon General, and the Comptroller General are identical: a reduction of the high rates of infant mortality among the poor through insured access to comprehensive prenatal care.

This administration contends that its poor standing in the Black community stems from misinformation and bad press. For the thousands of Black parents who needlessly lost their babies in the past several years, no amount of improved public relations can fill the emptiness they feel. Action--a solid program of preventive care available to all pregnant, poor women --will speak louder than words.

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[1] 138:23-24

VIII. REMEDIES

A. Introduction

Petitioners seek a host of administrative remedies which, taken together, could better insure that all poor, pregnant women have access to comprehensive prenatal care. Some of the proposed measures merely seek clarification and elaboration of options currently available to the states which, despite their obvious cost-effectiveness, have not been implemented. Through aggressive leadership and careful coordination, the federal government could encourage the states to implement changes which would maximize the use of both federal and state dollars for maternal and child health. Other proposed measures would mandate standards for comprehensive prenatal care and insure, wherever possible within the limits of federal authority, their implementation.

Initially, petitioners set forth a proposal for extensiv coordination among current programs through the appointment of a Select Coordinator. The petition's remedies are then discussed programatically under Title V, Medicaid, EPSDT, and nurse-midwives. Finally, petitioners propose a national education campaign.

B. Coordination

Despite continuing, resounding exhortations from all corners of the health delivery system and from oversight agencies for improved federal coordination of health program serving low income pregnant mothers and infants, the need remains unfulfilled. Yet, such coordination would be cost effective by eliminating duplication and ensuring that assistance would be targeted to the low income, high-risk pregnant women and infants who need it most.

Accordingly, petitioners request the institution of the following measures which HHS is empowered to implement through its rulemaking authority:

a. Designation by the Secretary of Health and Human Services of a Select Coordinator for Improving Pregnancy Outcome. The Select Coordinator, formally designated as Deputy Assistant Secretary for Maternal and Child Health, would have jurisdiction over the Health Care Financing Association (Medicaid), the Bureau of Health Care Delivery and Assistance (Title V, MCH, and Title X, Family Planning) the Office of Human Developmental Services (Title XX, Social Services Block Grants), the Office of Family Assistance (Social Security), and community and migrant health centers (Public Health Service). The Select Coordinator, appointed with the participation of petitioners and other interested persons who represent the high-risk population in question, would have ample influence and authority to coordinate all programs and funding sources serving low income mothers and infants and would provide leadership in the following areas:

(i) help develop the national education campaign (described *infra*, pp. 153 - 155) to promote the use of health care services essential to improving pregnancy outcome;

(ii) develop specific annual national goals and timetables to reduce low birth weight, particularly among low-income and minority mothers, and requiring state plans, whether Medicaid or Maternal and Child Health Block Grant, to describe how they intend to meet such goals and timetables;

(iii) develop a clearinghouse and provide technical assistance to assist states in replicating programs which have been effective in reducing infant mortality and low birth weight.

b. In addition, the Select Coordinator, working with individual HHS agencies, should oversee the development and promulgation of the following rules to ensure coordination of programs:

(i) the establishment of a uniform definition of comprehensive prenatal care, to govern the delivery and financing of maternity services under all programs administered by HHS including but not limited to the Maternal and Child Health Block Grant, Medicaid, Medicare, EPSDT, Title V, Title X, the Adolescent Family Life Program and Community and Migrant Health Centers;

(ii) as a condition of federal financial participation, require the State Medicaid and Title V agencies to adhere to the uniform Comprehensive Prenatal Care definition (*infra*., p. 146) in providing or financing prenatal care services under these programs;

(iii) require assurances from states in their state plans that services provided under Medicaid and the Maternal and Child Health Block Grant are coordinated so that:

- (a) related services will be housed together whenever feasible in easily accessible locations with hours convenient for most patients;
- (b) pursuant to 42 U.S.C. § 1396a(a)(11), State Medicaid agencies shall grant qualified provider status to all Title V providers meeting otherwise applicable provider qualification standards; and pursuant to 42 U.S.C. § 705, shall require that all qualified Title V clinical providers shall participate in the Medicaid Program;
- (c) Title V providers will be required pursuant to 42 U.S.C. § 705, when the services they offer are less than those offered by Medicaid providers covered under HHS's

Comprehensive Prenatal Service definition, to refer:

(1) Medicaid eligibles to other Medicaid providers for such comprehensive services; and

(2) for non-Medicaid eligible patients to refer such patients to providers, including providers of in-patient services, who will furnish care at little or no cost;

(d) Medicaid reimbursement will constitute "first dollar" coverage for all Comprehensive Prenatal Care services furnished by publicly funded providers including Title V funded providers, community health centers, migrant health centers and providers funded under Title X of the Public Health Service Act.

C. Title V

Since the passage of OBRA (Omnibus Budget Reconciliation Act) of 1981 and TEFRA (Tax Equity and Fiscal Responsibility Act) of 1982, the federal government has frequently approved state plans which are merely carbon copies of the statute and provide no real assurances of meeting the objectives of Title V. To ensure meaningful compliance, pursuant to §42 U.S.C. §705(1), the Secretary should promulgate rules implementing the Title V statute which, at a minimum, would require that a State Plan:

(1) is based on a needs assessment that identifies the geographical location of those in greatest need, what those unmet needs are, what providers already exist, where they are located, what services they provide and their capacity, what other health-related programs exist, and an assessment of the transportation available to reach providers;

(2) in assessing which communities are in need, utilizes a standard of "high-risk" which is defined by the Secretary in federal rules in accordance with commonly recognized medical standards;

(3) allocates funds to service sites in a manner that maximizes convenience, defined by the Secretary to take into account location, hours, and transportation services available;

(4) includes a coordination plan for services which maximizes resources, accommodates scheduling and transportation problems, and ensures that patients transferred between programs are not lost;

(5) requires that clinical providers satisfy the Comprehensive Prenatal Care definition for adequate staffing ratios to insure sufficient provision of services;

(6) provides for the training and use of community outreach workers;

(7) complies with criteria promulgated by the Secretary for assessing whether or not a state's expenditure of Title V funds on prenatal services is reasonably sufficient for the state to meet its annual goal of reducing the incidence of low birth weight and infant mortality [B(1)(a)(ii), supra];

(8) assures that there will be no discrimination in hiring, in providing services, and in closure or relocation of services;

(9) provides that data is collected to identify unmet needs;

(10) complies with rules which the Secretary will promulgate implementing the "free care" and "sliding scale fee" requirements of the statute.

D. Definition of Comprehensive Prenatal Care

Provision of comprehensive prenatal care should be part of each state plan. Every state should provide adequate assurances that it will deliver, at a minimum, the following services:

- physical examinations once every 4 weeks for the first 28 weeks of pregnancy, every two weeks until the 36th week and weekly thereafter;
- routine laboratory tests including blood and urine analyses;

- screening and counseling regarding nutrition, substance abuse, genetic abnormalities, and family planning;
- education on topics, including but not limited to training in labor and delivery, breastfeeding, use of medication, infant care and parenting;
- a psycho-social assessment;
- labor/delivery services available in a hospital or clinic;
- a follow-up exam for the mother, which includes family planning education and services;
- a well-baby exam;
- sufficient ratios of qualified staff-to-patients are maintained to provide the above described services.

E. Medicaid

Medicaid funds most maternal and child health care needs for poor women in this country. Repeatedly, Medicaid has been shown to increase dramatically minority and low-income women's access to health care which, in turn, has significantly improved their health status and that of their infants.[1] Severe budget cuts have reduced the numbers of mothers and children served just when the feminization of poverty has produced a greatly expanded need for health care coverage.

The declining percentage of poor pregnant women and infants covered by Medicaid[2] stems not only from budget cuts but from the federal government's failure to encourage state extension of coverage despite the genuine cost-effectiveness of doing so. Many options currently available to states would enable much greater numbers of low income women and children to be served, but the federal government's failure to clarify coverage possibilities has impeded the expansion of coverage.

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[1] 150:68

[2] 8:27

Petitioners request that HHS formally issue an eligibility rule for pregnant women which would encourage expansion of coverage for pregnant women and infants by clearly delineating the following options:

1. Coverage for Financially Needy Pregnant Women.

42 U.S.C. §1396d(a)(viii) and 42 U.S.C. 1396a(a)(10)(A)(iii) enable states to extend coverage to all pregnant women who do not satisfy the AFDC categorical test but whose income and resources are at or below state AFDC levels. This option would cover both single and married pregnant women, thus halting the misguided federal policy of requiring coverage only for single-parent families, a policy which has forced many husbands to abandon their wives so that their children are not denied health care. It would also cover first-time pregnancies, another category which has been inappropriately limited.

2. Coverage of Medically Needy Pregnant Women and Children.

The 1981 Medicaid amendments provide that states can institute a medically needy program limited to maternity care for pregnant women and ambulatory services for children

(42 U.S.C. §1396a(a)(10)), without assuming responsibility for the entire medically needy population. As such, the cost of instituting a medically needy program for pregnant women and children would require minimal additional expenditures. Any state which chose to implement options one and two would then have a Medicaid program covering all poor, pregnant women. If, despite the known cost-effectiveness of such a poicy, a state declined to establish eligibility for all poor, pregnant women, the federal government should clarify the following, less comprehensive options:

3. Coverage for First-Time Pregnancies.

While a woman pregnant for the first time often cannot obtain AFDC at all or only obtains it during her last trimester, Medicaid benefits can nevertheless be provided from the time pregnancy is determined, 42 U.S.C. §1396a(a)(10)(C)(ii)(II). This group constitutes a subset of all financially needy pregnant women. A state that declines to expand coverage to all financially needy pregnant women still might choose to cover this category, which frequently would include first pregnancies of adolescents. Teenage pregnancy is inherently high risk; babies born to those under 15 are almost twice as likely to die in infancy and to be of low birth weight than babies of mothers in their twenties. Comprehensive prenatal care has consistently reduced these risks.

4. Coverage for Financially Needy Children and Pregnant Women

42 U.S.C. §1397a(a)(10)(A)(ii) and 42 U.S.C. §1396d(a)(1) provides that states may cover "financially needy" children as optional categorically needy beneficiaries. These children are defined by law as children who meet their state's AFDC financial eligibility criteria, but who are not "dependent" as defined by Title IV-A of the Social Security Act. States can cover all of these children and pregnant women or reasonable categories of such women and children. Extending coverage to financially needy children would mean access to much needed prenatal and baby care. Specifically under this option, states could cover pregnant, married women and pregnant adolescents from two-parent families.

5. A Medicaid Standard for Comprehensive Prenatal Care.

The Select Coordinator should insure that women receiving their prenatal care either through Title V or Medicaid are provided comprehensive prenatal care. The mechanism for insuring this through Title V was previously discussed, *i.e.*, making comprehensive prenatal care a component of each state plan (see *supra*, pp. 144 to 146). An identical standard of comprehensive prenatal care can be established through Medicaid and EPSDT by amending current regulation 42 CFR 440.230(b) which requires that all Medicaid programs provide services sufficient in "amount, scope, and duration" to achieve their purposes, to include the definition of comprehensive prenatal care, supra, p. 146.

F. EPSDT (Early and Periodic Screening, Diagnosis and Treatment)

EPSDT provides for regular health assessments for all persons under the age of 21 and is mandatorily available to all categorically needy Medicaid eligibles. These health assessments include screening, laboratory work, and appropriate treatment. To insure that these preventive measures are fully accessible, EPSDT requires specific outreach efforts and assistance with transportation and scheduling.

Through clarification of options and establishment of standards, EPSDT could be used to insure prenatal care and well-baby care for a number of women and infants who might otherwise not be covered. Petitioners specifically propose the following:

1. Service Options Under EPSDT

HHS should clarify through regulations that those teenagers normally eligible for EPSDT screening and treatment should receive appropriate OB-GYN services through the program, including family planning services and, if pregnant, prenatal care.

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2. Mandatory Comprehensive Prenatal Care

Currently, HHS requires that, at a minimum, treatment provided through EPSDT include vision, dental, and hearing services, 42 CFR 440.230. HHS should expand the mandatory treatment categories to include comprehensive prenatal care provided for all EPSDT eligibility categories. Additionally, comprehensive prenatal care should include all of the components set forth above for Medicaid and Title V, supra, pp. 146 to 147.

3. Well-Baby Care and Infant Hospitalization

EPSDT already requires that each eligible baby receive a neonatal examination, i.e., an exam within the first 28 days. Through regulation, HHS should expand this requirement to include in addition to the neonatal exam the accepted schedule for the entire first year of well-baby care promulgated by the American Academy of Pediatrics.

Additionally, HHS should clarify that the neonatal examination provided for newborns under EPSDT constitutes an EPSDT "screen" which would then permit states to provide those infants with unlimited diagnosis and treatment including hospitalization, if necessary.

G. Nurse-Midwives

In order to maximize the use of nurse-midwives in providing prenatal care and obstetrical services to eligible

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women, HHS should issue the following rules:

1. as a condition of participating in the Medicare Program, states where nurse-midwives are legally authorized to practice to deliver babies should require all hospitals which receive Medicare reimbursement to provide admitting privileges for nurse-midwives;
2. similarly, in those states where nurse-midwives are legally authorized to practice to deliver babies, all Hill Burton Hospitals should be required to provide admitting privileges under their community services requirement;
3. amend current 42 CFR 440.220 to require that prenatal care services provided by nurse-midwives shall be reimbursable not only for the categorically needy, as it presently reads, but also for the medically needy. This expansion would only apply in those states where nurse-midwives are legally authorized to practice to provide such prenatal services.

H. National Educational Campaign

The federal government has already demonstrated its capacity for successful campaigns which combine public information and persuasion. It is the rare American who does not know and comprehend Smokey the Bear's message: "Only you can prevent forest fires!"

Similarly, the Department of Health and Human Services' Office of Health Promotion, in conjunction with petitioners and the Administrative unit responsible for maternal and child health pursuant to 42 U.S.C. §708(a)(c), can play a critical role in developing an education campaign which will provide information to pregnant mothers and the public at large about, but not limited to, the following topics:

1. The importance of early and comprehensive prenatal and neonatal care;
2. Identification and description of the varying conditions which are responsible for high-risk pregnancies;
3. Where to go and whom to contact to become Medicaid eligible and/or obtain publicly funded services for pregnant women and newborns;
4. Nutritional requirements during pregnancy with dietary suggestions tailored to the varying populations at risk;
5. The availability of publicly funded food programs which can assist pregnant women in obtaining or maintaining adequate nutrition during pregnancy, including WIC and food stamps;
6. The potential risks during pregnancy of smoking, alcohol, and the use of drugs, whether by prescription, over-the-counter or bought on the street; and
7. The availability of specific programs serving pregnant teenagers.

The wording should be simple, appear in languages other than English, and include graphic illustration wherever possible. The use of radio, TV and billboards, in addition to traditional posters and printed brochures, is essential. In sum, development of a multi-media campaign, thoughtfully designed to reach the greatest numbers of those at highest risk for pregnancy outcome, should be initiated immediately. Such a campaign will allow people to make informed choices about their lives, and the lives of their children.

I. Additional Federal Dollars

The cost effectiveness of the WIC Program, of prenatal care provided through Title V and of nurse-midwifery training has been demonstrated in other portions of this petition. Each of these programs has suffered cut-backs and/or severe erosion through inflation. While this petition is directed to HHS' capacity to take administrative action, petitioners cannot present a complete picture of the remedies without emphasizing the need for renewed federal funding in these three areas.

J. Additional Federal Legislation

Petitioners emphasize that the proposed remedies set forth above do not include legislative approaches which could definitively enhance this country's capability of reducing low birth weight and infant mortality, especially among the low income, minority population. By focusing on administrative solutions, petitioners in no way suggest that legislative approaches are not also necessary and urgent. Petitioners address administrative remedies because of their immediate potential for implementation. Nonetheless, petitioners believe that the evidence they present constitutes a compelling case for Medicaid reforms for mothers and children, the funds for which have been included by Congress in the first budget resolution for fiscal year 1984.

Dated: June 29, 1983.

Respectfully submitted,

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By ____________________
On Behalf of Petitioners

By ____________________
On Behalf of Petitioners

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APPENDIX

The table below consists of representative data from the Public Advocates Survey. Included are total live births and deaths for Blacks and whites and infant mortality rates for the 45 cities surveyed for 1980. The entire data set includes 1978-1981. Additional data is still being collected and analyzed by Dr. Jeffrey Gould at the University of California School of Public Health. Inquiries regarding that data and publication thereof may be directed to him.

Infant Mortality Rates for 45 Cities Studied

	1980
1. New York*	
White total live births	53,446
White infant deaths	801
White IMR	15
Black total live births	43,466
Black infant deaths	791
Black IMR	18.2
2. Washington, DC *,**,***	
White total live births	1,373
White infant deaths	17
White IMR	13.1
Black total live births	7,884
Black infant deaths	209
Black IMR	26.6
3. Seattle, WA	
White total live births	4,447
White infant deaths	52
White IMR	11.9
Black total live births	963
Black infant deaths	16
Black IMR	16.8